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IDENTIFIERS	Second European Conference Rehab Internl

ABSTRACT

The conference proceedings of the 2nd European Conference of Rehabilitation International (1978) on the theme disability in the family contains the agenda and approximately 80 papers. National presentations consider the theme in papers by representatives of Finland, Hungary, Belgium, The Netherlands, Portugal, Hong Kong, India, The German Democratic Republic, France, Italy, and Norway. Seminars usually involved 2 to 6 presentations each and were on the following topics: information and communication, medical aspects, spinal injuries, occupational therapy, deafness, congenital disability, transportaion, general aspects, legal aspects, services, employment, education, psychological factors, housing, sexual problems, emotional problems, technology, mental handicap, therapy, mobility for the disabled person, and prevention (the theme for the 1980 conference). "Free papers" cover additional topics. Other countries represented in the topical papers include the United Kingdom, Israel, the United States, Sweden, Denmark, Greece, Ireland, Romania, and Peru. (PHR)

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ED177756

Conference Proceedings

U.S. DEPARTMENT OF HEALTH,
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NATIONAL INSTITUTE OF
EDUCATION

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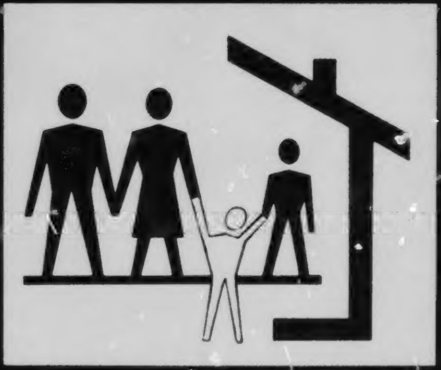
2nd European Conference of Rehabilitation International

Conference theme: 'Disability in the Family'



VENUE: The Brighton Centre and Hotel Metropole, Brighton, England.
September 18th, 19th, 20th, 21st, 1978

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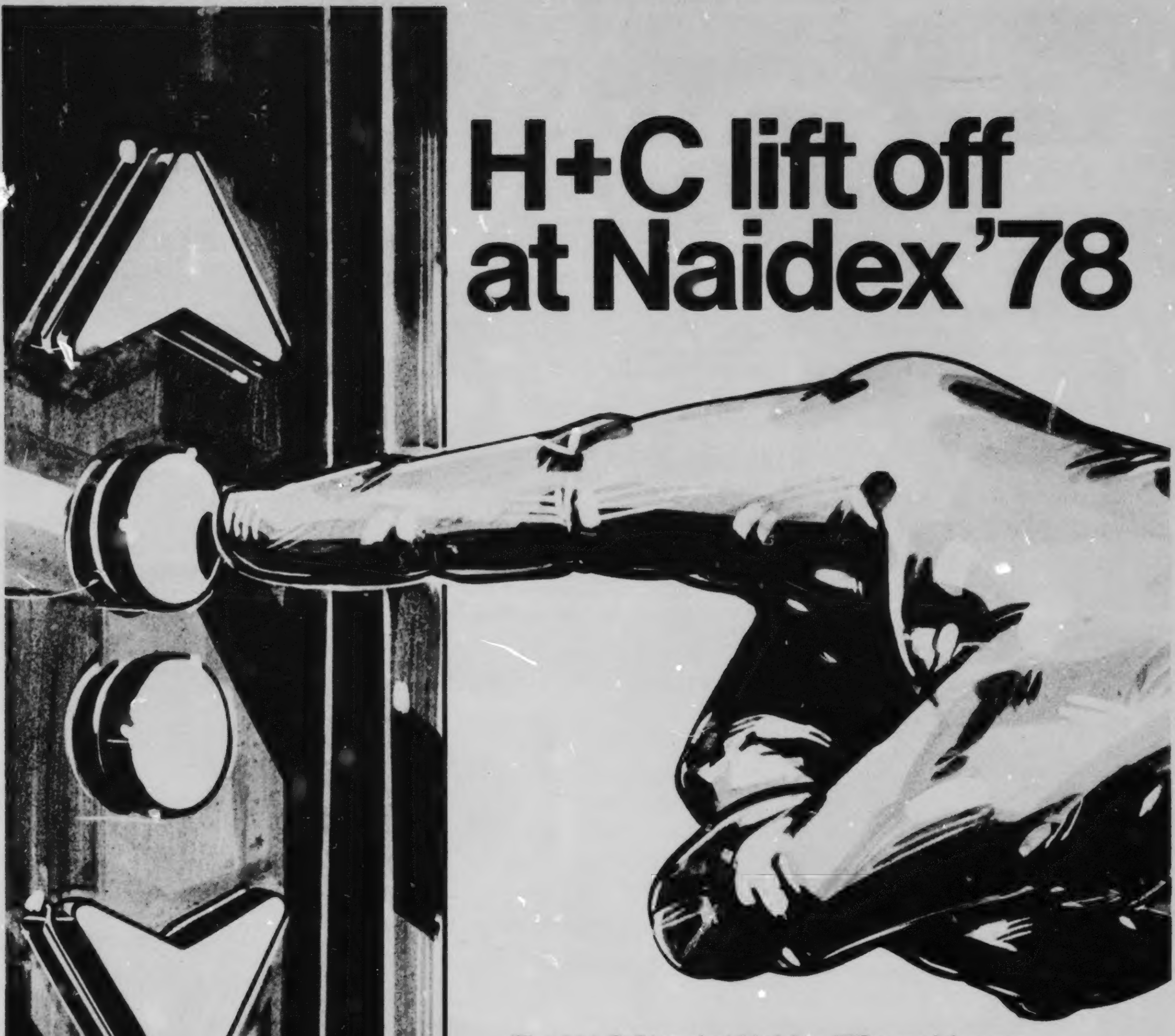

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Homelifts

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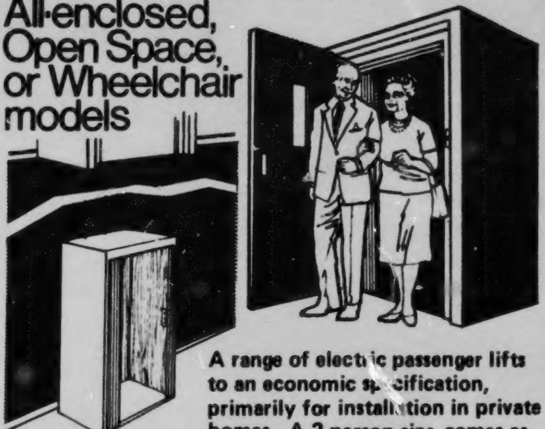

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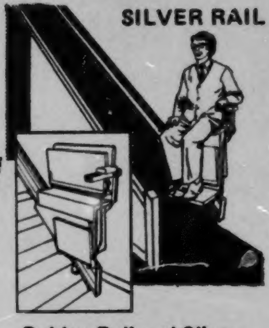
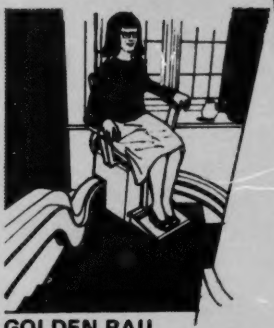


SILVER RAIL



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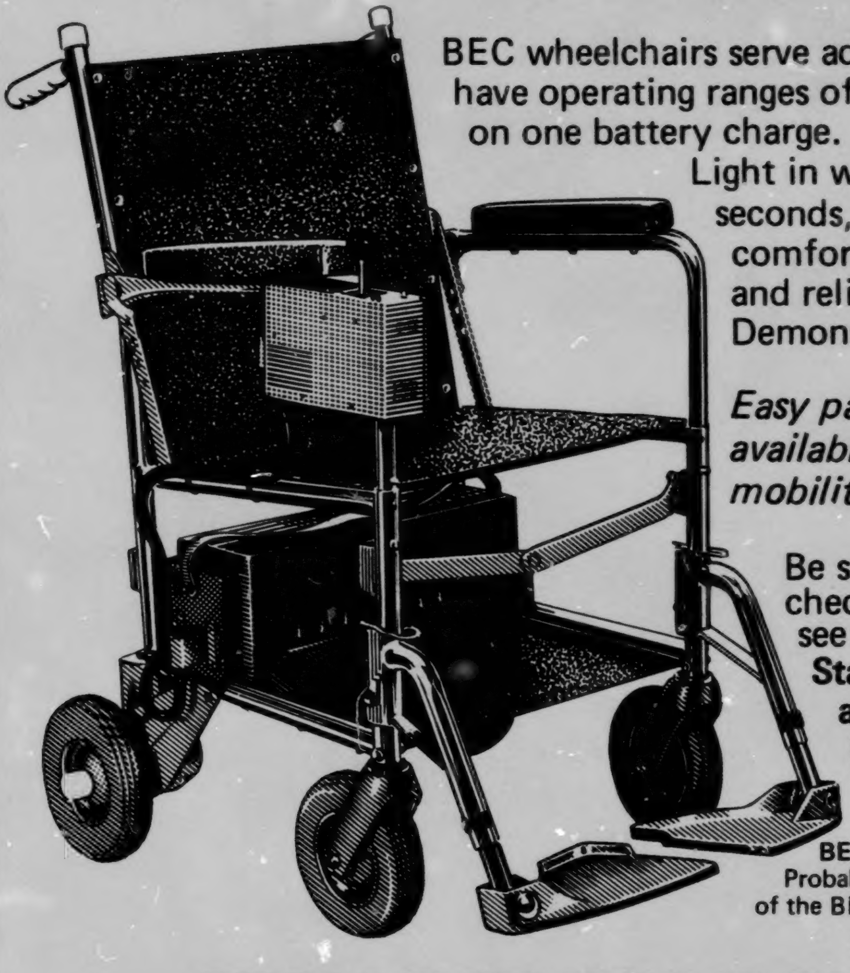

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Conference Proceedings

2nd European Conference of Rehabilitation International

Conference theme: 'Disability in the Family'

VENUE: The Brighton Centre and Hotel Metropole, Brighton, England.
September 18th, 19th, 20th, 21st, 1978

Sponsored by: The Royal Association for Disability and Rehabilitation.
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Papers not covered in these proceedings will be available after the conference

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WELCOME FROM THE CHAIRMAN OF THE ROYAL ASSOCIATION FOR DISABILITY AND REHABILITATION, HIS GRACE THE DUKE OF BUCCLEUCH, VRD.

The view is often expressed that conferences and meetings are of little value and nothing emanates from them. The opposite view is that no one can live in isolation and we only flourish and increase our knowledge by an interchange of experience and expertise.

Progress in the rehabilitation field over the years has been such that it is now a complicated and involved subject with many facets. It involves every aspect of life and all age-groups and has an infinite variety of permutations and combinations within its general theme.

It seems unlikely that anyone could attend our conference and not leave wiser and enriched and with an increased awareness of latest trends and developments; given an enthusiasm to continue to improve services and standards and with a deeper understanding of the many problems.

Above all the interchange of ideas and mutual discussion which springs spontaneously from any gathering can only be of benefit. It allows us to recharge our batteries, provides encouragement in the realization that problems which were thought unique are common to others and that our seemingly insoluble difficulty has been satisfactorily resolved elsewhere. It allows the discussion of problems against a background which can give differing emphasis and may set them in a different light and set of values.

We know that our meeting will provide us with that hope without which all rehabilitation must fail and that we shall all return home having renewed friendships and acquaintances, having exchanged opinions with those who have been but names to us, having heard differing points of view, explanations of ideals and above all new ways of dealing with a variety of problems and difficulties.

As Chairman of the Royal Association for Disability and Rehabilitation I can only welcome you to our meeting in the hope that it will further the cause of rehabilitation and allow us to feel that we have made yet one more step towards our elusive goal.

Buccleuch

PROGRAMME

Monday 18th September

Hall 1, Hotel Metropole 10.30–11.00	**OPENING CEREMONY** Chairman: His Grace the Duke of Buccleuch, VRD. Welcome by: The Right Worshipful Mayor of Brighton, Cllr. Alfred Feld Opening by: The Lord Goodman, CH Greetings from: Mr. Kenneth T. Jenkins, President of Rehabilitation International
11.00–11.30	'Disability in the Family' Mr. Alfred Morris, M.P., Minister for the Disabled United Kingdom
Hall 1, Hotel Metropole 2.00–3.30	**NATIONAL PRESENTATIONS** Chairman: Mr. K. T. Jenkins 'Disability in the Family' Frau Anke Fuchs, Secretary of State, Der Bundesminister für Arbeit und Sozialordnung, Federal Republic of Germany 'Disability in the Family' Finland
3.45–5.15	**NATIONAL PRESENTATIONS** Chairman: Mr. K. T. Jenkins 'Disability in the Family' Hungary The Belgian Social Rehabilitation Scheme for the Handicapped Mons. A. Maron, Director General-Director of Administration of the National Fund for the Social Rehabilitation of the Handicapped, Belgium 'Disability in the Family' Mr. W. J. Menken, LL.M., Management Assistant on Social Security, Ministry of Social Affairs, Netherlands
5.30–6.00	'Disability in the Family' Mr. H. Scicluna, Principal Administrative Officer, Partial Agreement Division, Council of Europe
Hall 2, Hotel Metropole 2.00–3.30	**NATIONAL PRESENTATIONS** Chairman: Dra. Teresa Selli Serra 'Disability in the Family' Portugal 'Disability in the Family' Prof. Dr. sc. med. K-H. Renker, Director of the Hygiene Institute and Vice-Dean of the Medical Faculty, Martin-Luther-University, Halle-Wittenberg, German Democratic Republic

3.45–5.15 **NATIONAL PRESENTATIONS**
Chairman: Dra. Teresa Selli Serra

'Disability in the Family'
Mons. J. Fourdjet, Sous-Director de la Readaptation,
Vieillesse et Action Sociale, Ministre de la Sante, France.

'Disability in the Family'
Italy

'Disability in the Family'
Dr. Tor Ødegaard, Dept. of Social Medicine,
Directorate of Public Health,
Royal Norwegian Ministry of Social Affairs, Norway.

Tuesday 19th September
SEMINAR 1
Foyer Hall, Brighton Centre

9.30–11.00 **INFORMATION AND COMMUNICATION**
Chairman: Air-Commodore D. F. Rixson, OBE, DFC, AFC.

Isolation in the Family Environment—the Role of the Provincial Newspaper
F. A. Saunders, ACA, RD, RMR.

Problems of Communication in Chronic Illness
Michael R. Bury, ARC Epidemiology Unit,
Manchester University.

11.15–12.45 **INFORMATION AND COMMUNICATION**
Chairman: Mr. C. J. Carey, Dip.S.Sc., MBASW, MISW.

Disabled Information and Advice Line (DIAL)
John Grant,
Chairman, DIAL Information

Breaking Barriers to the Employment of the Handicapped.
Hilary Schlesinger, Spastics Society.

2.00–3.30 **INFORMATION AND COMMUNICATION**
Chairman: Cllr. F. Long

The Difficulties of Information Provision for the Disabled and their Families.
Julie Spicer/Sheila Cooper, Institute for Consumer Ergonomics,
University of Technology, Loughborough

3.45–5.15 **INFORMATION AND COMMUNICATION**
Chairman: Prof. Dr. sc. med. K-H. Renker

The Information Services of Rehabilitation International.
Barbara Duncan, Director of Information,
Rehabilitation International.

Generalised Control and Information System for use by the Handicapped.
Chris Evans/Julia Howlett, National Physical Laboratory.

5.30–6.00 **FREE PAPERS**
Chairman: Dr. M. Naomi Wing, MB, BS, DPRM

Air Travel for the Disabled
Mrs. Zipora Brun
Rehabilitation International, Israel.

USA Independent Daily Living Program
David Williamson, Department of Housing, USA.

SEMINAR 2

Hall A, Brighton Centre

9.00–10.00 **MEDICAL PAPERS:**
Chairman: Dr. J. G. Sommerville, MD, FRCP

The Problems in Wheelchair Prescription
Dr. P. Dollfus, MD, Chief Consultant,
Centre de Readaptation, Mulhouse, France

11.15–12.45 **SPINAL INJURIES**
Organised in conjunction with the Spinal Injuries Association
Chairman: Mons. Jean Regniers

Disability in the Family—Rushed off my Feet
Mrs. Enid P. King, SRN, SCM, HV

Disability in the Family
Mr. Brian Lewis

2.00–3.30 Chairman: Dr. T. M. Gregg MD, FRCPI

Spinal Cord Injury and Peer Counseling/Peer Education
Mr. John Schatzlein, University of Minnesota

28/38 Grove Road: Accommodation and Care in a Community Setting
Mr. Ken Davies
Co-ordinator, DIAL Information and National Association of Disablement Information and Advice Services

3.45–5.15 Chairman: Mr. P. H. Bolshaw, CBE.

Disability, Adjustment and Family Life—Some Theoretical Considerations.
Mr. M. Oliver, Sociologist,
University of Kent

Disability in the Family
Mrs. W. Howarth
Vice-Chairman, Spinal Injuries Association

5.30–7.00 **OCCUPATIONAL THERAPY**
Chairman: Miss Peggy Jay

Major Adaptations and how they can be Avoided:
Professional Liaison between Architects and Occupational Therapists
Miss Rosemary Barry, Head Occupational Therapist and County Adviser on Services for the Handicapped,
Berkshire Social Services

A Community Occupational Therapy Service
Mrs. Jean Higgins,
County Organiser of Rehabilitation Services,
Surrey County Council

SEMINAR 3—Organised by the Royal National Institute for the Blind

Hall 1, Hotel Metropole

9.30–11.00 Chairman: To be confirmed

Advice to the Newly Blind
Bengt Hoflin, Swedish Federation of the Visually Handicapped

11.15–12.45 The Visually Handicapped Family and the Environment
Svend Jensen, President, Dansk Blindesamfund

2.00–3.30	Specialised Services for the Blind E. J. Venn, Royal National Institute for the Blind
3.45–5.15	Rehabilitation of the Multiple-Handicapped Blind Rev. Coote, Royal Leatherhead School for the Blind
5.30–7.00	**FREE PAPERS** Chairman: Mr. J. M. Blackwell Development of Independent Daily Living Skills and the General Maturing of the Severely Handicapped Teenager Barbara Newman and Jill Vernon, The Association for Spina Bifida and Hydrocephalus

SEMINAR 4—Organised by the Royal National Institute for the Deaf.
Hall 2, Hotel Metropole

9.00–11.00	**DEAFNESS** Chairman: Mr. J. Foote Rainbows after Storm—The Rights and Responsibilities of Deaf People who are also Blind Dr. Richard Kinney, Chairman, Deaf/Blind Council of the World
11.15–12.45	Chairman: Cllr. J. T. Rogers Film: 'Psychiatry for the Deaf' Dr. J. Denmark, Consultant Psychiatrist, Whittingham Hospital, Lancashire
2.00–3.30	Chairman: Mr. Roger Sydenham Excluding and Including the Deaf (from and into the family circle) The Rev. Canon T. H. Sutcliffe, Royal National Institute for the Deaf
3.45–5.15	Chairman: Mr. P. C. Trietline Title: To be confirmed Mme. Joxette Chalude, ANPEDA, France
5.30–7.00	**FREE PAPERS** Chairman: Mr. G. Gilbertson, CBE Mobility Needs of Disabled People in the UK—A Formal Sample Survey R. W. Gormley/Larry Walters, Lucas CAV Ltd.

SEMINAR 5—Organised by the International Cerebral Palsy Society
Hall 4, Hotel Metropole

9.30–12.45	**CONGENITAL DISABILITY** The responsibilities and aims of a parent group—Starting a new parent group and the work of a mature one Speakers: Dra. Teresa Selli Serra Associazione Italiana Per L'Assistenza agli Spastici. Mrs. Daphne Economou Spastics Society, Athens Provision of short term care within the community—a new experiment to be shown on film Speaker: Mrs. Barbara Garrett Senior Social Worker, Somerset County Council Social Services Department

2.00–5.15 Building and running a toy library for cerebral palsied children
Speaker: (to be confirmed)

Pre-school provision for handicapped children—the importance of the mixed play group
Mrs. Barbro Ekstrom, Folke Bernadotte Home, Upsalle, Sweden

Disabled children—Counting the Cost, a practical paper on transport, laundry costs, the 'extras' needed by a family with a handicapped child
Mrs. Sally Baldwin, Department of Social Administration, University of York.

5.30 I.C.P.S. A.G.M.

Wednesday 20th September

SEMINAR 1
Foyer Hall, Brighton Centre

9.30–11.00 **TRANSPORTATION**
Chairman: Group Captain R. E. Gardiner, DFC

The Development of Technical Adaptations of the Motor-car to the Requirements of Handicapped Persons
Mr. Zevering, Technical Advisor,
Rehabilitation Institute, Muiderpoort, Netherlands

Traffic Arrangements and Difficulties for the Handicapped
Jan F. van Leer, Consultant,
Nederlandse Vereniging voor Revalidatie

11.15–12.45 **GENERAL**
Chairman: Dr. E. P. Quibell, OBE, MRCS, LRCP, DCH

The Young Person, Disability and Family Relationships
Harold H. Wilke, U.S.A.

Family Behaviours in Severe Disability—A Perspective for Family Development
Dr. Paul W. Power, Director,
Rehabilitation Counseling Program, University of Maryland

2.00–3.30 **LEGAL**
Chairman: Mr. G. Gilbert

Legal Aspects of Rehabilitation Facilities Concerning the Family Development of Disabled People
B. van Buggenhout, Lecturer, Catholic University Louvain, Belgium

A Parliamentarian Looks at Disability
Lewis Carter-Jones, M.P.

3.45–5.15 **SERVICES**
Chairman: Mr. A. Kates, FRCS.

Identifying the Difficulties Created by Hanidcaps in the Family and Relating them to the Need for Care and Services
Dr. Margaret Agerholm, MA, BM, BCL(Oxon),
Consultant in Handicap & Rehabilitation—Heenan House,
Consultant in Rehabilitation—ILEA

Financial Provision for Disabled Families
Mrs. Jean Simkins, Senior Research Consultant,
Economist Intelligence Unit

SEMINAR 2
Hall A, Brighton Centre
9.30–11.00

EMPLOYMENT
Chairman: Mr. T. Jeffries

The Family and its Role in Decision Making regarding Occupations for the Disabled
Prof. Dr. sc. med. Ursularenate Renker,
Ordinary Professor of Industrial Medicine,
Martin-Luther-University of Halle Wittenberg,
German Democratic Republic

An Approach to the Employment of Disabled People in Britain
Dr. Silvester, Personnel Director,
Remploy Limited

11.15–12.45

GENERAL
Chairman: Dr. C. D. Evans

Disability in the Family
Dr. Ann Raikes, MRCP, MRCS,
Developmental Paediatrician, Poole General Hospital

Disability in the Family—The Changing Scene
W. H. Laming, Director of Social Services,
Hertfordshire County Council

2.00–3.30

EDUCATION
Chairman: Mrs. M. C. Clark

Access to Higher Education is by Attitudes rather than Architecture
Miss Judy Crosby/David Spooner, University of Sussex

The Rutland Street Project
Mr. Seamus Holland
Senior Inspector of Schools, Department of Education, Dublin

3.45–5.15

PSYCHOLOGICAL
Chairman: Dr. B. Ridsdale

Psychological Response to Illness and its Effects on the Outcome of Occupational Rehabilitation
Charles Burdett, Clinical Psychologist, Leicestershire Area Health Authority
Christopher Olsen,
Occupational Psychologist, Leicester Rehabilitation Centre

The Problems and Challenges in Taking Care of the Elderly Disabled—The Case of the Single Caring Daughter.
Miss Heather McKenzie, LL.B., Administrative Director,
The National Council for the Single Woman and her Dependants.

SEMINAR 3
Hall 1, Hotel Metropole
9.30–11.00

HOUSING
Chairman: Dkfm. Otto Geiecker

Mobility Housing
Selwyn Goldsmith, Superintending Architect,
Department of the Environment

Aspects that Play a Part in Adapted Housing of the Handicapped
Mr. J. Lips, Ministry of Culture and Social Work,
Netherlands

11.15–12.45

GENERAL

Chairman: Dr. R. Hudson Evans, MA, FRCS, LRCP.

Help of the Disabled and their Families at Home—
A Domiciliary Physiotherapy Research Project
Denis Smith, FRCP/E. Sonia Glossop,
Northwick Park Hospital

W.I.'s in Hospitals for the Subnormal and Cheshire Homes
Mrs B. Copestake
The National Federation of Women's Institutes

2.00–3.30

SEXUAL PROBLEMS

Chairman: Mr. R. Travers

The Problems that Parents Experience in Coping with the Sexuality of their Disabled Children
Dr. Wendy Greengross, Committee on Sexual Problems of the Disabled

Sexuality and the Handicapped
David Stock, Assistant Professor,
Baylor College of Medicine, U.S.A.

3.45–5.15

EMOTIONAL PROBLEMS

Chairman: Mr. J. Sarney, CAE

The Effects of Disability to the Concept of Social Psychology
John Stewart, Association of Disabled Professionals

Disabled Families
Mrs. E. Topliss, Senior Lecturer,
Department of Sociology and Social Administration,
University of Southampton

5.30–7.00

PLENARY SESSION

Chairman: Dr. the Hon. Harry S. Y. Fang

The Disabled Elderly in a Changing World
Dr. R. Glyn Thomas, DPH
Regional Officer for Development of Community Services,
World Health Organisation

International Year for Disabled Persons—1981
Mr. Esko Kosunen, Officer in Charge,
Secretariat, International Year for Disabled Persons,
Division of Social Affairs, United Nations

SEMINAR 4
Hall 2, Hotel Metropole
9.30–11.00

TECHNOLOGY

Chairman: Mr. P. J. Lowe

The Application of Modern Technology to Rehabilitation
A. J. Solman, S.M.I.L.E.

System for the Deaf
ir. A. S. Kruijf

11.15–12.45

TECHNOLOGY

Chairman: Mr. A. R. C. Rowe

Myoelectric Controlled Hand Prostheses in Children—
Clinical Considerations
Dr. Rolf Sörbye, Department of Clinical Neurophysiology,
Orebro Regional Hospital, Sweden.

Utility of a Communication Aid to Comprehension and Co-operation in Family Life and the Trials and Tribulations of its Manufacture
Prof. Oliver Butler/J. F. Fouldes, University of Sheffield

2.00–3.30

NATIONAL PRESENTATIONS

Chairman: Mrs. C. R. C. Harris

Integrating the Disabled Within the Community: The Hong Kong Approach
Ian Strachan, Principal Assistant Secretary for Social Services, Hong Kong Government

Disability in an Indian Family
Raghunandan Prasad, India Institute for the Physically Handicapped

3.45–5.15

FREE PAPERS

Chairman: Mrs. Greta Nordlie

Social Diagnosis and Therapy in the Reinsertion of Handicapped People into the Family Life
Professor Dr. Octavian Berlogea,
Institute of Medical Assessment and Rehabilitation of Work Capacity, Bucharest, Romania

Integration of the Physically Handicapped Child in the Family and Community in a Developing Country
M. Graca Andrada/Antonia Goulas, Portugal

SEMINAR 5
Hall 4, Hotel Metropole,
9.30–11.00

MENTAL HANDICAP

Chairman: Miss M. R. Morgan

Day to Day Living with a Handicapped Child
Gloria Calthorpe

Training Parents as Behaviour Modifiers for Severely Retarded Children
Shlomo Katz, Bar-Ilan University, Israel

11.15–12.45

MENTAL HANDICAP

Chairman: Ole Petter Lossius

Social Work Support for the Families of Mentally Handicapped Children and Adults
Jo Campling, BA, Lecturer in Social Policy
Hillcroft College, London

Counseling Services for Parents of Mentally Retarded Children
Ruben Reyes, Peru

2.00–3.30

THERAPY

Chairman: Dr. E. Helander

Mrs. Christiane Besson
Assistante Sociale—Pro Infirmis, Lausanne
Miss Anne Spuhler
Assistante Sociale—Pro Infirmis, Lausanne
Swiss Multiple Sclerosis Society

The Summer Family Conference—
An Experience in Counseling Families of the Handicapped
Leslie D. Park, Executive Director,
The United Cerebral Palsy Society of New York City, Inc.

3.45–5.15

MOBILITY FOR THE DISABLED PERSON

Chairman: Dr. A. V. Stokes

Thursday 21st September

Hall 1, Hotel Metropole
9.30–10.00

PREVENTION—INTEGRATION PRIORITIES FOR THE '80s

Introduction
Mr. Jack Sarney, CAE
National Executive Director,
Canadian Council for Rehabilitation of the Disabled

10.00–11.35

ROUND TABLE DISCUSSION
Priorities in Rehabilitation Needs

11.40

CLOSING CEREMONY

Foyer Hall, Brighton Centre
12.00

PRESENTATION OF HARDING AWARD TO GROUP CAPTAIN LEONARD CHESHIRE, VC, DSO, DFC

DAILY LECTURE PROGRAMME

Hall	10.30	11.00–11.30	2.00–3.30	3.45–5.15	5.30–6.00	6.30	DAY
BC Foyer						Civic Reception	1
M1	Opening Ceremony	National Presentation	National Presentations	National Presentations	Council of Europe (P)		
M2			National Presentations	National Presentations			
	9.30–11.00	11.15–12.45	2.00–3.30	3.45–5.15	5.30–7.00		2
BC Foyer	Information	Information	Information	Information	Free Papers		
BCA	Medical (9.00–10.00)	Spinal Injuries	Spinal Injuries	Spinal Injuries	Occupational Thelapy		
M1	Blindness	Blindness	Blindness	Blindness	Free Papers		
M2	Deafness	Deafness	Deafness	Deafness	Free Papers		
M4	Congenital Disability	Congenital Disability	Congenital Disability	Congenital Disability	I.C.P.S. A.G.M.		
	9.30–11.00	11.15–12.45	2.00–3.30	3.45–5.15	5.30–7.00		3
BC Foyer	Transportation	General	Legal	Services			
BCA	Employment	General	Education	Psychological			
M1	Housing	General	Sexual Problems	Emotional Problems	U.N. & W.H.O. (P)		
M2	Technology	Technology	National Presentations	Free Papers			
M4	Mental Handicap	Mental Handicap	Therapy	Mobility			
	9.30–10.00	10.00–11.35	11.40	12.00			4
BC Foyer				Presentation of Harding Award			
M1	Prevention—Integration Priorities for the '80s	Round Table Discussion	Closing Ceremony				

(P) = Plenary Session

Halls: BC Foyer = Brighton Centre, Foyer Hall
BCA = Brighton Centre, Hall A
M1 = Hotel Metropole, Hall 1
M2 = Hotel Metropole, Hall 2
M4 = Hotel Metropole, Hall 4

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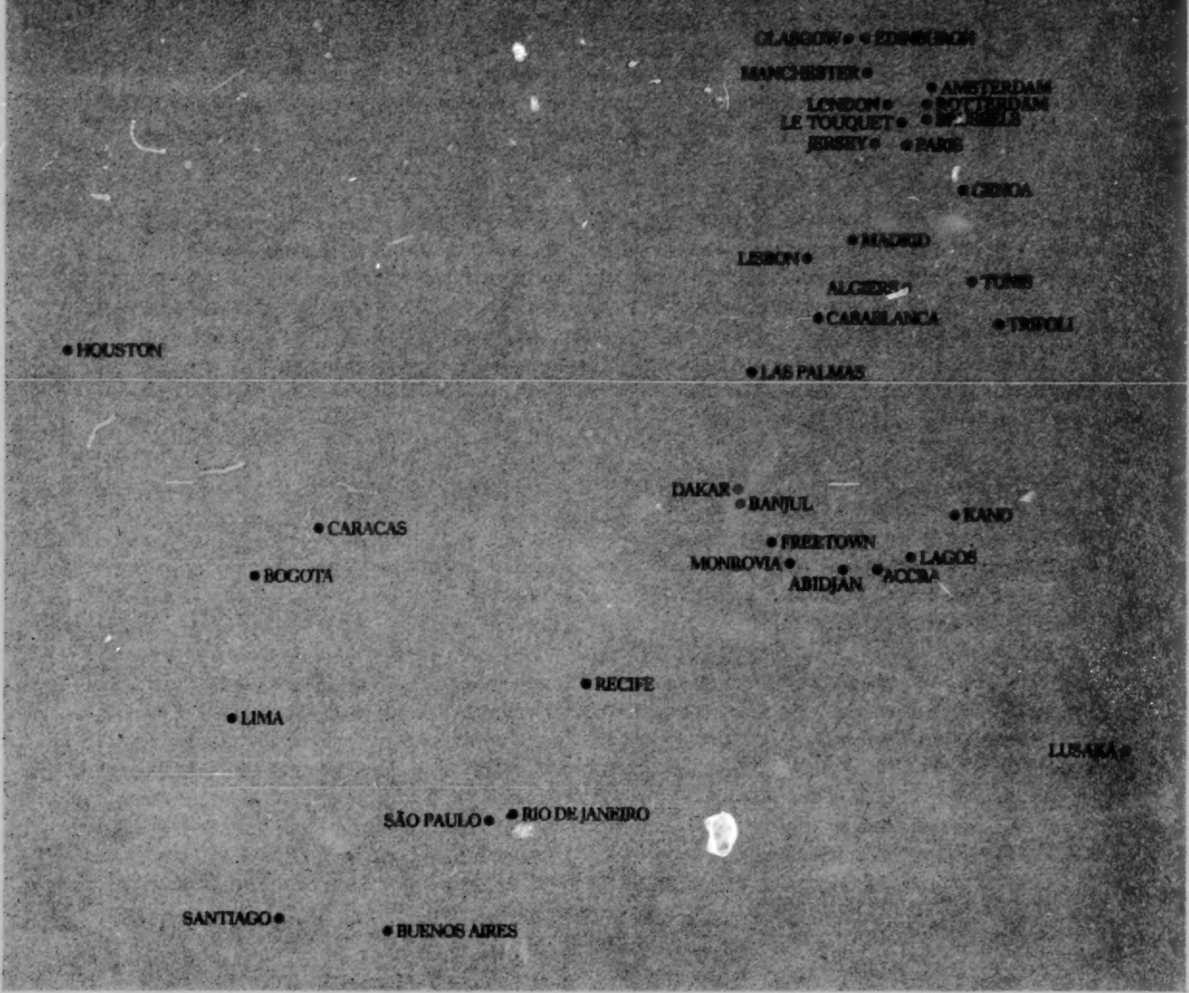
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NATIONAL PRESENTATIONS

Chairman: *Mr. K. T. Jenkins*

'Disability in the Family'
Frau Anne Fuchs

'Disability in the Family'
Finland

'Disability in the Family'
Hungary

The Belgian Social Rehabilitation Scheme for the Handicapped
Mons. A. Maron

'Disability in the Family'
Mr. W. J. Menken, LL.M.

'Disability in the Family'
Mr. H. Scicluna

NATIONAL PRESENTATIONS

Chairman: *Dra. Teresa Selli Serra*

'Disability in the Family'
Portugal

'Disability in the Family'
Prof. Dr. sc.med. Karl-Heinz Renker

'Disability in the Family'
Mons. J. Fourdjet

'Disability in the Family'
Italy

'Disability in the Family'
Dr. Tor Ødergaard

SPEECH BY ALFRED MORRIS MP, MINISTER FOR THE DISABLED, TO THE 2ND EUROPEAN CONFERENCE OF REHABILITATION INTERNATIONAL AND NAIDEX 1978, at BRIGHTON ON 18 SEPTEMBER 1978

It is both a pleasure and an honour to have been invited to give the opening speech at this conference. It is an occasion of very considerable importance for disabled people here and abroad. Britain itself is fielding a strong team of participants, but the conference is an international one and will be enriched by the thoughts of distinguished people from all over the world. Their fellowship in joining us here is deeply appreciated and, for Her Majesty's Government, I most warmly endorse Lord Goodman's eloquent words of welcome to all our guests from abroad.

My one regret is that it will not unfortunately be possibl[illegible] me to stay with you throughout the Conference. My thoughts will be [illegible] you, however, and I shall follow all your deliberations with the kee[illegible] interest. I shall do so not only as a British Minister concerned to do a[illegible] can further to improve the status and well-being of disabled people in this country, but also as Chairman of the World Planning Group which is to draw up a "Charter for the 1980s" for the world's 450 million disabled people. To achieve real progress in the decade ahead the Charter must reflect the views of disabled people themselves and their organisations throughout the world. Any thoughts you may wish to put to me, in my capacity as Chairman of the World Planning Group, will thus be most sympathetically and carefully considered.

Let me know say how delighted I am that you have chosen "Disability in the Family" as the theme of this conference. For disability is very much a family affair. By definition of the word family, if one member is disabled then the family as a whole is involved in the problems of disablement. In other words, show me a disabled person and I'll show you a disabled family. This is why disablement is not, as some may think, the problem only of a small minority. In this country today, there are upwards of 3½ million disabled people. Millions more are involved through family. Add to this the million people in our caring professions and it becomes evident that much more than a small minority of our people are daily involved in the difficulties to which disability gives rise. Moreover, potentially we are all disabled. In one way or another, almost all of us can expect to be disabled at some point in our lives. So we are met today to discuss the problems not of a minority, but of the majority of people here and across the world.

There is more and more concern in this country now to stress the importance of the family unit in any approach to the solution of social problems. Public discussion of the role of the family has recently been given a strong new impetus by the emphasis our Prime Minister has placed on its importance. This is a further reason why I am delighted by the theme of this conference. For the importance of family is nowhere more demonstrable than it is in the field of disablement.

I propose in my address today to couple the family theme with a look at some specific issues - integration, cash help and service provision, among others - and also to touch on what might be termed the "rights" of disabled people. It might be helpful if I begin with a very brief historical resume. In earlier, so-called "golden" days, society effectively rejected people who were chronically sick or disabled. We and many other countries still sometimes use the word "leper" as a synonym for an unwanted outcast. The disabled commonly had to beg to survive and mostly had to endure the added handicap of continuous and grinding poverty. In this country, it was not until the end of the nineteenth century that the State began to accept any real involvement in the care of disabled people. Even then its role was limited to certain aspects of industrial health, safety and welfare. Indeed, the Workmen's Compensation Act of 1897 was our first piece of legislation to include particular help for some disabled people. That Act is thus an important part of our social history. In the first half of the present century much more legislation - on health, education, housing, employment and cash benefits - was introduced and enacted. But the new laws were not directed specifically towards helping handicapped people. They were intended to raise standards generally. Other than the Disabled Persons (Employment) Act 1944, no specific legislation existed for disabled people before the enactment of the Chronically Sick and Disabled Persons Bill in 1970. My Bill could not have become law without the dedicated help of a very wide fellowship of people, from both sides of both Houses of Parliament as well as out of Parliament, who shared my determination to legislate for a better life for disabled people. Many of them are here today and I am glad to be able to express my renewed appreciation of their work.

Not only does our 1970 Act contain provision for identifying disabled people, but within its twenty-nine sections it gives far reaching help in the fields of housing, education, employment and access, as well as the personal social services. Although many of the fields dealt with by the Act are the direct concern of other Ministers and other Government Departments, I myself now have an overall, co-ordinating responsibility to Parliament, as Minister for the Disabled, not only for services that flow from the Chronically Sick and Disabled Persons Act but also for all other services and care for disabled people. This enables my Department to see the full range of need in a way which would otherwise be impossible.

In the view of most people, the most important provisions of our Act are those in Sections 1 and 2. The first of these requires local authorities, who are responsible for providing personal social services in this country, to identify the numbers and needs of disabled people living in their areas and to publise the services available to them. Section 2 lists specific services which must be provided by local authorities where they are satisfied of need in any individual case. These services include adaptations to the homes of disabled people and the provision of telephones, television, holidays and personal aids. The main purpose of Section 2 is to enable disabled people to remain in their own homes, among their own families and friends, and thus to live their lives as freely and normally as possible.

Yet perhaps we should start at the beginning. For many families, experience of disability starts with the birth of a disabled child and, over recent years, we have been developing in Britain comprehensive assessment services for our disabled children. Our aim is to enable the disabled child to be seen by specialists from all the relevant disciplines together, so that his needs as a whole can be fully considered and an overall plan can be made for his future care and support. The child is seen as a child and not by reference to any specific type of handicap or impairment. This is especially important where, as in so many cases, disabled children have more than one kind of disability.

Services are generally based in the children's department of a district general hospital, but there are strong links also with local authority education and social services departments. We are now trying to take this joint approach a stage further with the establishment of District Handicap Teams. These were recommended by the Court Committee on Child Health Services in this country when they reported to the Government at the end of 1976. The recommendation won wide support among the organisations and people we consulted and we have asked authorities to implement it.

Turning for a moment to education, all of us know that a good education is the key which unlocks the doors to wider opportunity. Disabled children have the same right to a good education as anyone else and we do our best to give them every possible help. Integration has a special relevance here.

The idea of integration in our education system is not new. For over thirty years, successive governments have supported the principle that no handicapped child should attend a special school if his or her needs can be met in an ordinary school. This principle has now been given statutory expression in Section 10 of our Education Act 1976, which amends previous law by requiring that handicapped pupils are to be educated in ordinary maintained schools unless this would be impracticable, incompatible with the efficiency of the school or likely to involve unreasonable expense.

In higher and further education there is in general no segregation. Wherever access and facilities are adequate, disabled students attend the same courses in the same colleges as non-disabled students. One recent development is that some of our colleges are beginning to adapt certain regular courses to meet the particular needs of handicapped students. So far as cash help is concerned, the disabled student is eligible for the full range of mandatory and discretionary grants. In addition, our local education authorities have a discretionary power to augment mandatory grants within certain limits to meet extra expenses that arise from a student's disability.

Our Open University goes still further in that disabled students have always been exempt from the usual "first come, first served" basis of admission and also from the normal minimum age limit of 21. Extra tuition may be provided locally, instead of through attendance at summer schools, and examinations may be taken at home or in hospital. Moreover, a Liaison Committee with the Disabled was set up in 1970 and, in 1972, the Open University appointed a senior counsellor with specific responsibility for disabled students.

No matter how well we provide for the education of handicapped children and young adults, our concern and responsibilities must not stop there. Their quality of life is strongly influenced also by the suitability of their living accommodation. As disabled children become adults, and as adults become older, so the nature of the accommodation they need changes, just as it does for everyone else. In the past, this was almost totally ignored. Until the 1970 Act we had no housing legislation at all specifically for disabled people. All too often family life was disrupted or broken up by the problems of unsuitable accommodation. At the same time, large numbers of disabled people were unnecessarily expelled from society into institutions. The generality of disabled people have as much as other people to give to the family and indeed to the community at large. And our aim now, by encouraging good housing design and the adaptation of existing housing, is to make it possible for disabled people to play their full part both in family life and society generally.

We believe the housing needs of most disabled people can be met by what we call mobility housing. This is ordinary housing incorporating minimal design changes, for instance, flat or ramped access and wider doors and passage-ways. By building as many new houses as we can to this standard, we are widening the choice open to disabled people about where they can live. And like most other people, they mostly and quite naturally want to live among family and friends.

There are, however, some disabled people for whom specialised housing is essential. To meet their needs, we have developed what we term wheelchair housing. This is housing specially designed to meet the particular requirements of disabled people. Of course, not all disabled people want to move to a new house, which can mean leaving a familiar community. For people who prefer to stay where they are, adaptations are needed to make their homes more convenient and this help is available to them under the provisions of the 1970 Act and our general scheme for house improvements.

Turning now to the field of outdoor mobility, this is another very important key for disabled people. It is the key that unlocks the door to the outside world. We now have in Britain a new form of help namely the Mobility Allowance. In introducing this new benefit we are not only increasing our expenditure from £13 million in 1974 to an estimated £82 million by 1980/1, but are also helping very many more people. The introduction of the Mobility Allowance has stimulated other new initiatives on a much wider front and the private sector is now very much involved in outdoor mobility help for disabled people. We have a new, independent and very important organisation - Motability - which has been set up to help beneficiaries of the Mobility Allowance to acquire cars by means of a leasing scheme. I am glad that my Department played a part in the establishment of this challenging new organisation which has raised £100 million from the clearing banks to launch the scheme.

Transport facilities generally have improved tremendously in recent years. Motorways, inter-city rail services and domestic airlines all make long distance travel much faster. Our disabled people share in the benefits of these developments, but often not as much as other people because of problems of access. I am very pleased, therefore, that British Rail's new High Speed Train stock and their Mark III coach stock provide facilities to allow disabled people to travel in their own wheelchairs first-class for half the ordinary second-class fare. This is a useful step in the right direction and British Rail has demonstrated that it keeps the needs of disabled people constantly in mind in planning for the future.

We are also encouraging other public transport operators to meet the needs of disabled people in planning bus services and in the design of vehicles. In fact, a special requirement has been included in our new Transport Act that traffic commissioners must have regard to the convenience of disabled people when exercising their bus licensing functions. This legislation makes various other changes in the law to facilitate car sharing and makes it easier for community bus services to operate successfully. Both these measures can be of considerable help to disabled people.

Work is proceeding to make bus entrances more readily accessible to disabled people. Now that previous legal requirements stipulating a lower limit to the step height of buses have been removed, there is no bar on operators and manfacturers making step and floor heights as low as possible. One of our passenger transport executives has introduced the "kneeling bus", modifying their air suspension system of their entire fleet of Leyland National Buses so that the front part of each bus can be lowered almost to the kerb at bus stops.

Car parking for disabled people was yet another problem tackled by the Chronically Sick and Disabled Persons Act, which brought into being our national Orange Badge Scheme. This scheme provides a number of important concessions for drivers and non-drivers alike by enabling badge-holders to park near to shops, offices or anywhere else they want to go. Britain now has some 250,000 orange badge-holders. But pedestrianisation schemes have been a cause for concern among disabled people who fear that they can reduce the value of the orange badge. We have in the past advised local authorities to take special account of the needs of the disabled where any such scheme is introduced. In particular, they have been asked to consider providing parking spaces for use by orange badge-holders as close as possible to the places they need to visit. But what can be done depends very much on local circumstances and the local authority on the spot has to try to be the best judge of these.

There is, of course, much left to be done further to improve mobility help for disabled people. Financial constraints have limited the scope of the Mobility Allowance to the most severely disabled. We know thare are many others who can walk but still have difficulties in getting about out of doors. Again, the new allowance is available only up to pension age. But we cannot solve all problems overnight. We have made marked advances in improving provision and will make further progress as soon as we can. Only by giving disabled people the means to independent mobility can we hope to see them taking a full and more fulfilling part in society.

I turn now to other cash benefits available to disabled people.

In the United Kingdom, we have a fully integrated Social Security system which provides a wide range of cash benefits for disabled people and their families. Tax-free income maintenance benefits, with increases for dependants, are available to practically all people of working age who are incapable of work, regardless of the cause of illness or the nature of a person's employment. These benefits are not conditional, as in some countries, on a person's willingness to undertake rehabilitation or training. Nor are they payable only for a limited period. Provided a person remains incapable of work, his benefits may continue in payment until replaced by retirement pension.

These benefits are not, however, the only financial provision for disabled people. In the past decade, a very great deal has been done to enable our most severely disabled people to be cared for in their own homes rather than in hospitals and other institutions. For those who need a great deal of care or supervision, we have an Attendance Allowance which is payable to people of all ages in addition to the maintenance benefits, such as those for sickness or retirement, which they may be receiving. Since it is designed specifically for people being cared for at home, the Attendance Allowance ceases to be payable during a prolonged stay in hospital where attendance needs are met free-of-charge to the patient under the National Health Service. Maintenance in a hospital or institution is both extremely costly and also socially undesirable unless it is absolutely necessary. We have, therefore, as a further incentive to help disabled people to stay within the family and the community, introduced another benefit which is called the Invalid Care Allowance. This is payable to men and single women who stay at home to care for a severely disabled relative who is receiving Attendance Allowance. A still further new benefit we have recently introduced is the Non-Contributory Invalidity Pension, which is of particular value to the congenitally handicapped who have never been able to work.

There is a wide range of new financial help now available. Even so, there is widespread hope, that we may be able to introduce a general disablement allowance in the future. There is strong pressure also for a special new Blindness Allowance. A recent development of relevance to the question of further assistance for disabled people was the publication of the Royal Commission on Civil Liability and Compensation for Personal Injury.

We are currently studying this Report in depth and consulting widely about its recommendations. I have heard many objections to certain points of the Report's recommendations - particularly those which relate to compensation for road accident victims - on the grounds that they would lead to a new "elite" among disabled people and pre-empt resources which might otherwise be used for a general disablement allowance. We have not yet concluded our deliberations on the Report, but I and my Ministerial colleagues are very well seized of the concern of many organisations of disabled people about the consequences of following all of the Report's recommendations.

You will understand from all of this that there is a considerable interest in this country in making further changes and improvements to the structure of financial help for the disabled. And this is how it should be, because a secure financial base is an essential feature of stable family life. Another such feature is the ability to be able to get in and out of buildings and, when inside them, to be able to move around freely. It was for this reason that my Act included five sections on improving access to public and social buildings of all kinds. These sections affect the responsibilities of every local authority, and of almost every Department of State, by placing specific obligations on local and central government. They place obligations also on all sorts of statutory committees, councils and boards, as well as on architects and developers. Not only does the Act require anyone providing a public building to make provision for access by disabled people but, in addition, suitable parking and toilet facilities must be available "insofar as it is in the circumstances both reasonable and practicable". These requirements were extended in 1976 to include places of employment. All developers are thus required by law to give particular attention to the needs of disabled people and to ways of meeting their needs. This in turn helps to stimulate a much wider public awareness of the difficulties that disabled people have to face.

Our legislation applies, however, only to new developments. And it is usually in existing buildings that difficulties arise. Most of our town halls, churches, public libraries, community centres and hotels are, of course, much older than the Chronically Sick and Disabled Persons Act. Some are completely inaccessible to wheelchair users, while others create often minor but always annoying and frustrating difficulties. Yet often only a small and inexpensive structural change - such as the installation of a ramp or wider doorways - is needed to overcome the obstacle. Sometimes the only real change needed is a change of attitude on the part of the proprietors. Sheer prejudice is frequently at the root of much discrimination against disabled people. Some examples I have come across are still more reminiscent of mediaeval society's objection to the leper than of the 20th Century's reputation for providing a caring society.

This is why public attitudes are so important and why I established last year our Silver Jubilee Committee on Improving Access for Disabled People. The Committee worked hard and successfully to promote greater public awareness of the access barriers that still face disabled people and to show how, with a little imagination and ingenuity, most of them can be overcome. In an intensive one-year campaign, the Committee made the question "Can Disabled People Go Where You Go?" one of real impact and meaning.

As I have said, not all access problems are caused by physical barriers. The attitudes of shop owners, of managers of cinemas and of theatres and other amenities are just as crucial a determinant of whether or not a disabled person can get into public and social buildings. This reminds me of a quote from some schoolchildren who took part in a competition organised by the Silver Jubilee Committee:-

> "We learned", said the children, "that the disabled and infirm have an enemy more deadly than hostility. They often have the extra handicap of public hypocrisy ....".

The Silver Jubilee Committee has achieved a great deal since I set it up. Inevitably it has concluded that more needs to be done. It is currently finalising its report, which will describe what it has done and what it has concluded about the present situation. Although I have not yet seen the Report, I understand that it is likely to include comments and views on the question of tackling discrimination against disabled people and on the possible merits of further legislation in this field. There are two schools of thought about legislation. Some disabled people like the possibility of something along the lines of our Equal Opportunities Commission, although with expanded terms of reference. Others take the view that further legislation to protect their specific and special interests is undesirable. Since they want to be seen as part of the general community and to live their lives as normally as possible, they see any measure calling for their interests to be separately safeguarded as a step in the wrong direction. They also feel that, although in some respects progress is slow, the most likely way of achieving the objectives of complete integration is by educating the general public toward improved attitudes. They fear that legislation could well turn out to be counter-productive.

My own view is that both legislation and public education have a part to play. Legislation can help considerably in improving public attitudes, as the Chronically Sick and Disabled Persons Act has demonstrated, and indeed it is sometimes the only way of achieving a limited objective. But it would be very difficult to carry legislation whose primary aim was to enforce the changing of attitudes.

Nevertheless I have taken careful note of all the suggestions I have already received and look forward to reading what the Silver Jubilee Committee have to say in their Report. I understand the Report will include recommendations for action not only by the Government, but by a number of bodies in the public and private sectors. As I have said, when I receive the Report I shall be studying it with the greatest care and sympathy. I fully expect that it will make an invaluable contribution to my assessment of priorities for action to make access to a full life a reality for all our disabled people.

Of course, it is no good making practical provision to allow disabled people access to public buildings if they are then debarred through existing fire or other regulations. While it is proper that adequate safeguards are taken, we must ensure that there are reasonable balances. It is in any case impossible to guarantee 100 per cent security. We must recognise that public buildings exist for social purposes. They are there to enable people to make the most of their opportunities for living. And by people I mean not only the able-bodied but also disabled people as well.

Many disabled people point out that, if they are successfully to overcome the difficulties which their disabilities cause, they must be able to use public and social buildings as freely as everyone else. They acknowledge that there are risks but, like other people, they feel they have the right to decide what risks they should expose themselves to and that it is not for others to tell them what they should do. The risks, such as they are, should be faced. I realise that people who are responsible for safety in buildings will require considerable courage in adopting this line, but we should not let ourselves become neurotic on the issue of risks.

I have this morning only briefly touched on some of the difficulties which face disabled people and the steps we are taking in this country to minimize their problems. There is no time for me to do more. You may, however, find it helpful if I leave with the Conference copies of a summary of the new help for disabled people which has been made available during my time as Minister for the Disabled. The list illustrates the diversity of the tasks we have faced and the nature of our approaches to them. It is not an exhaustive list of the new help available. Nor does it represent a completed job. There is very much more for us to do and it is our intention to make further progress as rapidly as we possibly can. Nothing will give us a greater sense of urgency than our concern to strengthen and support disabled people in the context of family.

I started with a historical note. I end with one, too. Our social history is strewn with battles to enhance human dignity and to win human rights. These battles were not easily won. We may not always be immediately victorious in the battles we are now fighting. The struggle will probably be long, but we are steadily winning converts from the enemy, and our troops include everyone who cares about human rights. The disabled are on the march and justice alone requires that they must win.

CHECKLIST OF NEW HELP FOR DISABLED PEOPLE

The following checklist sets out the decisions and the action taken by this Government since March 1974, to provide new help for disabled people and their families.

Social Security

Non-Contributory Invalidity Pension (NCIP) for men and single women: now 130,000 beneficiaries.

Mobility Allowance for an estimated 100,000 new beneficiaries, including severely disabled children.

Introduction of Non-Contributory Invalidity Pension in lieu of 'pocket money' allowance for long-stay patients in mental hospitals: 56,000 beneficiaries.

Extension of Non-Contributory Invalidity Pension to married women incapable of normal household work: 43,000 beneficiaries to date.

Invalid Care Allowance for men and single women who look after severely disabled relatives: approaching 6,000 beneficiaries.

Social security benefits, including benefits for disabled people, up-rated five times since March 1974. Further up-rating in November 1978.

Raising of therapeutic earnings limit for recipients of Invalidity Pension, Non-Contributory Invalidity Pension and Unemployability Supplement.

Legislation enacted for earnings-related Invalidity Pension, an easing of the age conditions for Invalidity Allowance and 'home responsibility protection' for a person who has to stay at home to look after a relative needing care.

Increase in Private Car Maintenance Allowance for War Pensioners.

Attendance Allowance payable to foster parents of handicapped children as from 29 August 1977.

Increase in Car Maintenance Allowance for War Pensioners and others.

Industrial disablement benefit for victims of byssinosis (not extended to new categories).

Industrial Injury provisions for occupational deafness introduced and currently under review.

Industrial Injuries Advisory Council asked to consider whether asthma caused by exposure to substances encountered at work should be prescribed as an industrial disease.

Viral hepatitis prescribed as an industrial disease.

Vinyl Chloride Monomer induced diseases prescribed as industrial diseases.

Easing of conditions for entitlement to industrial death benefit in certain cases of death from pulmonary disease.

Study of the problems faced by disabled people in relation to membership of occupational pension shemes.

Other financial help

£9.6 million paid to Rowntree Trust Family Fund for disabled children.

Extension of terms of reference of Rowntree Trust Family Fund to include all severely disabled children.

Government Help for Thalidomide children.

Vaccine damage payments scheme.

Coal Industry Pneumoconiosis Compensation Scheme. Limited right of appeal on diagnosis of pneumoconiosis introduced and proposals announced for extending right of appeal.

Financial Support of Voluntary Organisations

Much increased financial support for voluntary bodies.

Government financial support for Crossroads Care Attendants Schemes.

First-ever grants to three major voluntary organisations for the hearing-impaired.

Grants for three voluntary organisations helping to find adoptive parents for handicapped children.

Grant to assist Royal Association for Disability and Rehabilitation, formed by merger of the Central Council for the Disabled and the British Council for Rehabilitation of the Disabled.

Grant to the Scottish Council on Disability, including assistance towards Mobile Aid Centre.

Grants for Scottish Workshop for the Deaf conference.

Grant to the Scottish Council for Spastics for the provision of Sheltered Housing for disabled people.

Co-operation and Consultation

Better co-ordination between Government Departments.

UK co-sponsors UN Declaration of 1981 as an International Year for Disabled Persons.

Closer liaison with voluntary bodies.

Wide-ranging Seminar on Disablement held at Sunningdale.

UK co-sponsors UN Declaration on the Rights of Handicapped People.

Approaches to non-government organisations.

DHSS/Post Office Liaison Committee on aids for the physically and sensory handicapped.

Personal Social Security Council's new group on "People with Handicaps".

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Hearing Impairment

Phasing-in of new behind-the-ear hearing aid for up to one million hearing-impaired people: over half a million already supplied.

Special hearing aids for children and young people.

Advisory Committees on Hearing Impairment.

Institute of Hearing Research and first English out-station established.

Audiological Medicine - a new specialty.

Development of audiology services.

Co-ordination with DES on audiological equipment in schools.

Guidance for Hearing Aid Users.

Up-dating of NHS hearing aids.

Hospital Ear Nose and Throat Services - Design Guide.

Introduction of Hearing Therapists.

Staff Training on Deafness.

Government help for the Private Mambers Bill to enable the Hearing Aid Council to draw up a code of practice to govern advertising of privately dispensed hearing aids.

Visual Impairment

Increase in Blind Person's tax allowance.

Capital grants proposed for pilot residential units for deaf-blind adolescents and young people.

New NHS Optical arrangements of special help to people with severe loss of vision.

Appointment of additional Blind Persons' Training Officers.

New Government circular to local authorities about admission of guide dogs to certain premises.

British Rail agree to admit guide dogs to sleeping cars.

Mental Handicap

National Development Group for the Mentally Handicapped set up.

Development Team for improving services available to mentally handicapped people.

Programme Planning Group on Mental Disorder.

Jay Committee on Nursing and Care of the Mentally Handicapped.

Aids

Funding of Special Units at selected hospitals to work specifically on aids and equipment.

Assessment of Aids and Equipment for Physically Handicapped People at Rehabilitation Centres.

DHSS assumes financial responsibility for 'Equipment for the Disabled' from the National Fund for Research into Crippling Diseases.

More environmental control aids made available for disabled people.

Advisory Group on Medical and Scientific Equipment and Aids and Equipment for the Physically Disabled.

Development and general introduction of cosmetic calipers for NHS patients.

Improvements to wheelchair service.

Review of wheelchair service.

Development of a swivel-walking device for spina bifida patients.

Catalogue of and guide to environmental control equipment for the severely disabled.

Working Group on patient support systems.

Study of personal hygiene and eating aids at Loughborough.

Development of a chemical closet for home use (production started in February 1977).

Study of stairlifts and personal passenger vertical lifts for disabled people.

Mobility and Transport

Further parking concessions for all 'Orange Badge' holders.

Extension of 'Orange Badge' scheme to include the blind.

Petrol allowance restored (and doubled) for drivers of government-supplied invalid vehicles.

Financial and administrative support for major new voluntary organisation: Motability.

Extension of exemption from Road Tax (vehicle excise duty) to Mobility Allowance beneficiaries or their nominees.

Exemption for certain disabled people from the statutory restrictions on car hire-purchase and rental or leasing terms.

Disabled people now automatically entitled to priority in taking driving tests.

Provision of facilities for disabled people at motorway service areas (including signing them on motorways).

Concessions to 'Orange Badge' holders at most tolled crossings.

Disabled drivers now able to supervise 'L' drivers.

Two distinctive traffic signs prescribed and supplementary signs, exempting disabled people from vehicle traffic prohibitions, may now be used.

Public Transport - Special arrangements for disabled travellers by British Rail, and easier access into new rolling stock.

Concessionary fares for disabled people.

In consultation with the Government, London Transport review travelling problems faced by disabled people.

New bus design now being tested in London.

Government help for Private Member's Bill to exempt mini buses used by certain voluntary organisations from Public Service Vehicle Licensing Scheme.

Research study of the needs of disabled drivers and passengers.

Education

Introduction of discretionary allowance of up to £160 to disabled students whose disability leads to additional expenses in connection with their studies (to be increased to £180 on 1 September 1978).

Integrated education of handicapped pupils given new impetus by the passing of Section 10 of Education Act 1976.

Report of the Warnock Committee on education of handicapped children and young people published 24 May 1978.

Improved provision for the needs of disabled people in educational establishments.

Survey of Further Education provision for young adults with handicaps.

Guidance on the discovery of children requiring special education and the assessment of their needs.

Employment: Rehabilitation, Training and Job Opportunities

Publication by Manpower Services Commission (MSC) of "Positive Policies" - an employers' guide to employing disabled people.

Decisions on the future of the employment quota scheme, sheltered employment for disabled people and related matters.

Scheme of grants to employers towards the cost of adaptations to premises or equipment made to enable disabled individuals to obtain, or retain, employment.

The inception, on 4 July 1977, of an experimental Job Introduction Scheme, to provide financial assistance enabling certain disabled people to undertake a trial period of employment with an employer, where there is reasonable doubt as to the person's ability to perform a particular job.

A revised and simplified scheme designed to help severely disabled people with their travel to work costs introduced on 5 July 1978.

Increases in allowances paid to people going on employment rehabilitation courses.

Increase in the number of Senior Disablement Resettlement Officers in the Employment Service Division of the MSC.

Under the MSC Special Programme for young people additional opportunities have been provided at Employment Rehabilitation Centres for disabled young people.

Increased budget in the Employment Service Division for work in hospitals.

Arrangements made by Manpower Services Commission in co-operation with DHSS for hospital patients to spend part of each week at an ERC. Plans made to run young persons' work preparation courses at all ERCs.

Establishment of an employment rehabilitation research centre and the commencement of its research programme.

Planning in progress for rebuilding of the pioneer ERC at Egham. A new double-stream ERC has been built at Preston, opening Autumn 1978.

A systematic evaluation of Young Persons Work Preparation Courses has been carried out by the Hester Adrian Research Centre. Research commissioned by ESD in May, 1976.

Residential Training Colleges Working Group set up to examine the services they provide, their relationships with the employment and training services of the MSC and their role for the future.

Introduction of literacy/numeracy training at one RTC and decision to continue in view of the results achieved.

Introduction of special courses for the less able at one RTC (ITWE).

Introduction of a Pre-Vocational Assessment Course at one RTC.

Introduction of the Release for Training (RFT) scheme for disabled people who are already in employment but experiencing problems which can only be resolved by a period of intensive training.

Increase in provision of individual training - with employer arrangements.

Major expansion in the range of publicity material available to assist disabled people to obtain and keep employment, particularly the launch of the Employment Service Division's new rehabilitation and resettlement magazine "Outlook".

Publication in the DE Gazette of figures showing quota performance of public sector employers - nationalised industries, local authorities, area health authorities and Government departments.

Issue by the Civil Service Department of a Code of Practice on employment of disabled people in Government departments.

Research programme started on the training needs of disabled people.

On 1 April 1978, the MSC introduced its Youth Opportunities Programme which comprises a number of different schemes, including remedial courses, work preparation and work experience. Young disabled people are eligible for all elements of YOP and parts of the programme are specifically designed to help them.

Housing

Strong new guidance on housing needs.

Marked increase in special housing provision for disabled people.

Consultation paper on adaptations to housing.

Awards for good housing for disabled people.

Government help for the Rating (Disabled Persons) Act 1978.

DOE Circulars to New Town Development Corporations requesting greater provision within their tenancy allocation policies for housing elderly and disadvantaged families, including the physically and mentally handicapped.

Promotion of EEC-Funded Study of Housing and Care for disabled people.

Access and Designing for Disabled People

Appointment of Silver Jubilee Committee on Improving Access for Disabled People.

Awards for best public buildings for disabled people.

Government help for Private Member's Bill extending the access provisions of the Chronically Sick and Disabled Persons Act 1970 to places of employment.

Publication in June 1978 of technical guidance on designing and adapting government buildings to meet the needs of disabled employees and members of the public.

Pressure on public and other bodies to improve access and services for disabled people, eg special low counters for wheelchair users.

Improvement of facilities for disabled people in the National Theatre.

Home Office Circular on Access to Polling Stations.

Advice on the adaptation of premises to meet the needs of disabled employees has also been given to Employment Service Division for use by Disablement Resettlement officers in discussion with private sector employers.

Access for Disabled People - Design Guide and Wallchart.

Incorporation into building regulations of standards for ramps for wheelchair users and others.

Research

DHSS Research Liaison Group set up to look at research needs in the disablement field.

DHSS assumes financial responsibility for research team supporting work of Rowntree Trust Family Fund.

Research into Work, Personal and Social Difficulties of Handicapped People seeking employment - conducted by Neil Fraser, University of Edinburgh. (Due to finish December 1978).

Research on the relevance of services to disabled adolescents - conducted by Dr Dingwall and Professor Illsley, University of Aberdeen.

Miscellaneous

District Handicap Teams set up.

Extension of War Pensioners' visiting scheme.

Zero rating of VAT on aids and appliances for disabled people and also on medical equipment for donation to a hospital for the purpose of treatment or research.

Remedial professions - improved status.

New arrangements for Dental treatment of handicapped patients

The provision of special rehabilitation facilities at the Birmingham Head Injuries Centre for people who have suffered severe head injuries (in co-operation with Area Health Authorities).

Meeting on classification and assessment of impairment and handicap held in London in October 1976.

Extension of special concessionary TV licence arrangements for people in old people's homes.

Increasing the number of disabled people, or people representing their interests, appointed to the Nationalised Industries' Consumers' Councils.

Government's White Paper on Sport and Recreation of 1975; its emphasis on the needs of the disabled.

Issue of new edition of 'Help for Handicapped People' and 'Help for Handicapped People in Scotland'. Further revisions to be published in November, 1978.

~~August 1978~~ ALFRED MORRIS

18 SEP 1978

BACKGROUND NOTES

SOCIAL SECURITY

Non-Contributory Invalidity Pension

Non-contributory invalidity pension (NCIP) was the first of a series of new cash benefits which the Government introduced for chronically sick and disabled people and their families. It was based on the report on Social Security for Sick and Disabled People (published by HMSO as House of Commons Paper No 276 in September 1974), which outlined an evolving programme of action on the problems and needs of disabled people. NCIP is a non-means-tested, non-contributory benefit for chronically sick or severely disabled men and single women who have been incapable of work for such a long time - in many cases since birth - that they have not been able to build up a sufficient contribution record for a contributory benefit. It is payable at the rate of £10.50 (£11.70 from November 1978) a week (tax free), plus increases for a dependent wife and children. There are at present 130,000 beneficiaries.

Mobility Allowance

Mobility Allowance, introduced from 1 January 1976 is a non-means-tested, non-contributory benefit of £10 (from 5 July 1978) a week (taxable). It will eventually be available to severely disabled people aged five to pension age (60 for a woman, 65 for a man) who are unable or virtually unable to walk because of physical disablement.

The allowance is having to be introduced gradually by age groups and is currently available to disabled people aged five to 57 inclusive. By 20 December 1978 people aged five to 58 will have been included. The remaining groups, to pension age, will be included by stages and there will be announcements in the press in good time for claims to be made. When all groups have been included (by the end of 1979) Mobility Allowance will remove the major inequity of the invalid vehicles scheme which helped only those people who could drive. Approximately 71,000 people are now in receipt of the allowance. On 23 July 1976, it was announced in a Ministerial statement that the tricycle was to be phased out over the next few years and from the date of the statement, tricycles were no longer available to new applicants as an alternative to Mobility Allowance. As promised in the statement, amending legislation has now been passed enabling all those currently in receipt of a car, tricycle or private car allowance provided under the former invalid vehicle scheme, to switch automatically to Mobility Allowance if they wish to do so and to receive it without age limit.

Long-stay Patients in Mental Hospitals

Non-Contributory invalidity pension is providing at least 56,000 long-stay patients in mental hospitals, who are all of working age but incapable of work, with an allowance for their personal use of up to £3.05 a week. These patients have hitherto had to rely on hospital funds for any personal requirements; giving them non-contributory invalidity pension as of right ends a long standing and shameful anomaly. In addition if a newly admitted patient is without income of any kind, supplementary benefit is now made available to him for personal expenses.

Extension of Non-Contributory Invalidity Pension to Married Women incapable of their normal household duties

NCIP was extended in November 1977 to married women who are incapable both of their normal household duties and of paid work. Some 36,000 married women are receiving the £10.50 a week pension. It is usually known as HNCIP.

Invalid Care Allowance

Invalid Care Allowance (ICA) is a non-means tested, non-contributory benefit of £10.50 per week (£11.70 from November, 1978) (taxable) for men and single women who cannot go out to work because they have to look after a severely disabled relative receiving attendance allowance. ICA recognises that, just as disablement may prevent someone working so may the need to stay at home to care for a severely disabled relative. It has been payable since July 1976 with increases for dependents. Receipt of ICA protects a person's rights to contributory benefit in the future. There are currently approaching 6,000 beneficiaries.

Benefit Up-ratings

Benefits specifically for disabled people have been and will be up-rated as are social security benefits in general. There have been five up-ratings of social security benefits since this Government took office and there will be a sixth in November 1978.

Therapeutic Earnings Limit

Invalidity pension and non-contributory invalidity pension are payable to people who are totally incapable of doing any work for which an employer would pay them. The very great majority of beneficiaries earn nothing at all.

A small minority - most of them mental patients who have been in hospital for a long time - earn a little by doing things which are therapy rather than work and which keep them from vegetating. They could earn up to £4.50 a week net, without their benefit being affected, until April 1975; the 'therapeutic earnings limit' as it is called, at present £10 a week, will be raised to £11 a week in November 1978.

New Pension Scheme

The level of retirement and invalidity pensions is of obvious importance to disabled people. Provision has been made in the Social Security Pensions Act 1975 for a new pensions scheme, starting in April 1978, which will lead to better pensions in retirement, widowhood and chronic ill health. The new pensions will be in two parts, a basic pension equivalent to the present flat-rate pension and an additional earnings-related pension.

The basic retirement and widows pension will continue to depend on the payment of contributions or the award of credits, for example for sickness, in about nine-tenths of the number of years in the contributor's working life but an important new development is that basic pension rights will be safeguarded without any requirement to pay contributions when a person has to stay at home to look after a child or a relative needing care ("home responsibility protection").

Rights to the earnings-related pension will build up year by year over a period of 20 years. Earnings-related pension will first become payable in April 1979, based on earnings-related contributions payable from April 1978.

The age conditions for the invalidity allowance will be eased so that the highest rate will become payable for incapacity starting before age 40 and the intermediate rate for incapacity starting before age 50 (in place of the present age limits of 35 and 45 respectively). The change will take effect from 1979.

Increase in Private Car Maintenance Allowance for War Pensioners

Private Car Maintenance Allowances for war pensioners have been increased from £100 to £250 per year from 5 July 1978 and they will continue to receive exemption from vehicle excise duty. Since 1 January 1976 war pensioners have had an entirely separate scheme for mobility assistance under which they may apply for any of the benefits formerly available to them under the old vehicle scheme. Those who since then have qualified for mobility help and have chosen the private car allowance do not have the option to switch to the Mobility Allowance on special terms. It is for this group, for future war pensioner applicants and any war pensioners who are old scheme beneficiaries but do not wish to switch to Mobility Allowance that the private car allowance has been increased to £250 per year.

Increase in Car Maintenance Allowance for War Pensioners and Others

Rates of car maintenance allowance paid to war pensioners and other disabled people using cars issued by the Department were increased with effect from 15 July 1978. The new rates are £50, £90 and £150 a year in place of the former rates of £35, £55 and £65. Overall these new rates represent a doubling of car maintenance allowance although the rate for older cars is more than those for newer ones to help towards increased maintenance costs in the later stages of a car's life.

Byssinosis

Industrial disablement benefit for sufferers from cotton or flax byssinosis was extended in November 1974, so that benefit could be paid for an earlier stage of the disease, and with five instead of ten years qualifying employment. Any employment up to and including the winding or beaming process is now qualifying employment so that spinners are included. Where byssinosis relates to employment before 1948, the qualifying period of employment has also been reduced from 10 to five years by provision of the Social Security (Miscellaneous Provisions) Act 1977.

Provisions for Occupational Deafness

Disablement benefit under the industrial injuries provisions of the Social Security Act 1975 has been payable for occupational deafness - substantial sensorineural hearing loss due to noise at work.

The occupations covered are those involving the use of pneumatic percussive tools or high speed grinding tools on the dressing of castings; the use of pneumatic percussive tools on metal in the ship building and ship repairing industries; or work wholly with drop forging plant. About 13,000 workers are covered.

People who have worked for a minimum of 20 years in one or more of these jobs are at present covered for benefit, but in reply to a Parliamentary Question from Mr Edward Lyons (Bradford West) on 27 January 1976 Mr O'Malley the then Minister of State, at the Department of Health and Social Security said:

> "We have the problems of occupational deafness very much in mind and my rt hon Friend proposes to ask the Industrial Injuries Advisory Council to review the operation of the relevant provisions to date and to identify the processes where the noise levels are nearest in severity to those already covered with a view to extending categories as and when financial resources become available."

The Council was asked on 20 February 1976 to review the operation of the occupational deafness scheme. The Council's report was submitted in May 1978 and has been published. The report is receiving urgent and careful consideration.

Viral Hepatitis

From 2 February 1976 viral hepatitis has been prescribed as an industrial disease for people working in close and frequent contact with human blood or looking after patients ill with viral hepatitis.

Vinyl Chloride Monomer

From 21 March 1977, two diseases caused by exposure to vinyl chloride monomer - angiosarcoma of the liver and osteolysis of the terminal phalanges of the fingers - have been prescribed as industrial diseases for people working in buildings where the polymerisation of vinyl chloride monomer is carried out.

Industrial Death Benefit

Under the Social Security (Miscellaneous Provisions) Act 1977, where someone entitled to industrial disablement benefit for pneumoconiosis or byssinosis dies as a result of any pulmonary disease, provided the disablement due to pneumoconiosis, byssinosis or a combination of pneumoconiosis and tuberculosis was assessed at not less than 50 per cent death may be treated as having been due to the appropriately prescribed industrial disease. This will mean for such cases the removal of uncertainty which presently arises through the need to await determination, following postmortem examination, that death was caused by the industrial disease.

Occupational Pension Schemes

During the committee stage of the Social Security Pensions Bill, an amendment was moved which was aimed at securing unrestricted access to occupational pension schemes for disabled people suffering from non-progressive physical or sensory impairments. The amendment was withdrawn when the Government undertook to have a wide review of the problem carried out.

In May 1976, the Government asked the Occupational Pensions Board to study the problem in the following terms -

> "To consider and advise on what measures would be most conducive to the elimination of any unreasonable restrictions in the availability of occupational pension scheme cover to disabled people".

The Board are an independent statutory body, one of whose functions is to advise the Secretary of State on occupational pension scheme matters referred to them.

The Board's report was submitted in May - "Occupational Pension Scheme Cover for Disabled People" - and was published in June (Cmnd 6849). The report says that most employers accept the principle of "fit for employment - fit for the pension scheme", and that the evidence which the Board received indicated that there is no problem of any significant size in relation to occupational pension scheme cover for disabled people. The Board say in their report that they decided on practical grounds, not to recommend at this stage legislation or a formal code of practice on equal access for disabled people. But they have identified a number of areas where they would like to see improvements in pension scheme provisions, particularly as regards early retirement on grounds of ill health.

The Government are encouraged to find that a more informed attitude to the admission of disabled people to occupational pension schemes has developed among employers in recent years. The Minister for Social Security, Stanley Orme, has said that the Government accept that the improvements suggested by the Board should be brought about by voluntary action as recommended by the Board. He has also expressed the hope that the Board's recommended improvements will commend themselves to those whose schemes so far do not conform.

OTHER FINANCIAL HELP

Rowntree Trust Family Fund

The Rowntree Trust administers the Government-financed Family Fund for severely handicapped children. At first the resources of the Fund were available only to the congenitally handicapped but the Minister for the Disabled announced on 4 December 1974 the Government's decision to extend the Fund's terms of reference to include all handicapped children, regardless of the cause of disability. It is therefore possible for the parents of vaccine-damaged children, among others, to apply for help from this source. Since 1974 this Government has given £9.6 million to the Fund and a further £2 million will be made available this year.

Government Help for Thalidomide Children

The Thalidomide Children's Trust is responsible for the distribution of the compensation money paid to the families of Thalidomide Children by the Distillers Company. In January 1975, the Government made a payment of £5 million to the Trust to increase the income available to them in a way which would offset the effects of taxation. Like all severely handicapped children, thalidomide children may be eligible for help from the Family Fund, for attendance allowance and for mobility allowance.

In addition, in March 1978 the Minister for the Disabled, with the full agreement of the Distillers Company, appointed Sir Alan Marre, the former Ombudsman, to undertake an independent review of the outstanding 'Y' list cases (ie those children who had not, on the information available to Distillers at the time of the 1973 settlement, been accepted by the Company as thalidomide children but who would, if subsequently accepted, receive compensation on the same basis as the 'X' list children - ie those already accepted). Sir Alan's terms of reference were:

> "To consider what further steps it may be equitable and reasonable for the Distillers Company Limited to take in relation to any of the outstanding 'Y' list cases, and to make recommendations."

Sir Alan's report is expected before the end of the summer.

Vaccine Damage Payments Scheme

The Secretary of State for Social Services announced to Parliament on 9 May 1978 that the Government had decided to bring forward urgently a scheme of payments for vaccine damage. The scheme will provide for the payment of a tax-free lump sum of £10,000 in respect of persons who have, since 5 July 1948 been severely damaged as a result of routine vaccination in the United Kingdom against diphtheria, tetanus, whooping cough, poliomyelitis, measles, rubella or tuberculosis (BCG) or smallpox (up to July 1971 when its routine use ceased to be recommended).

Entitlement to attendance allowance or mobility allowance for conditions which could be attributed to vaccine damage will be accepted as the initial - but not the exclusive - criterion of severe damage. Decisions as to whether the severe damage was due to vaccination will be made on the balance of probabilities.

Details of the scheme and the arrangements for the making of claims will be announced when they have been worked out. It is hoped that payments will start before the end of 1978.

The Coal Industry Pneumoconiosis Compensation Scheme

The Coal Industry Pneumoconiosis Compensation Scheme was established by an agreement between the National Coal Board and the mining unions dated 13 September 1974. The Government made a contribution of £100 million towards the cost of the scheme.

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The Scheme applies to all persons who have worked for ten or more years in the coal industry and are certified as suffering from pneumoconiosis or silicosis. Where the disease developed before 1 October 1974, compensation is in the form of a lump sum, which varies according to the age of the man when first certified and his percentage disablement assessment. It reflects both compensation for pain and suffering and also for loss of earnings up to age 65. Dependants of men who have died are also entitled to a benefit in the form of a lump sum. Men who develop the disease after 1 October 1974, receive a lump sum to cover pain and suffering and a weekly allowance to cover loss of earnings. Dependents of men who die receive a dependants pension.

So far 64,000 claims have been paid at a cost of £125 million.

A limited right of appeal to independent medical appeal tribunals on the diagnosis of pneumoconiosis has been introduced. This has replaced the administrative arrangements under which certain difficult or doubtful cases could be referred to a Central Pneumoconiosis Medical Board. Proposals have been announced for extending the right of appeal as soon as possible.

FINANCIAL SUPPORT FOR VOLUNTARY ORGANISATIONS

More Financial Support for Voluntary Bodies

Despite the very difficult financial climate, Government Departments are doing their best to increase grants to worthwhile voluntary organisations in recognition of the services they are providing - services which would otherwise need to be provided by the State, almost certainly at greater cost. This is a practical demonstration of the Government's belief that it and the voluntary bodies must work in close partnership to secure progress in the development of services for disabled people.

Government Support for Care Attendant Schemes

The last two years have seen a rapid growth in the number of care attendant schemes, following the success of the original Crossroads Care Attendant Scheme in Rugby. The DHSS has since 1976 given the Rugby scheme financial support and in 1977 agreed to give the Crossroads Trust a three-year grant to assist the setting-up of a National Office. The Department is also making a financial contribution to the EEC-funded research project on the housing needs of disabled people (see page 26).

Grants to Voluntary Organisations for the Hearing Impaired

The Government recognises the importance of the work of the voluntary organisations for the hearing impaired. In July 1974 a grant, payable for three years from the date of take-up (1976) was made to the British Association of the Hard of Hearing to enable them to set up a Headquarters.

A grant to the Royal National Institute for the Deaf was authorised on 3 April 1975 towards the cost of correspondence exchanged with hearing impaired persons and their relatives about their problems and needs arising out of the television series 'I See What You Mean'.

In 1976 a three year grant was made to the British Deaf Association to help them set up courses in manual communication and to publish a definitive book of British Signs.

In 1977 a three-year grant was made to the Breakthrough Trust Deaf-Hearing Group to strengthen their HQ administration and to help meet the salaries of Field Officers.

Grants for those Voluntary Organisations helping to find adoptive parents for handicapped children

The Government recognised the need for special measures to encourage the adoption of physically and mentally handicapped children. During 1975 and 1976 grants over a period of years were authorised to three voluntary organisations involved in finding suitable adoptive parents to provide permanent homes and a family environment for mentally and physically handicapped children.

CO-OPERATION AND CONSULTATION

Liaison with Voluntary Bodies and Co-ordination between Departments

The appointment of Alf Morris as the first ever Minister for the Disabled has resulted in a much closer liaison between the voluntary bodies working on behalf of disabled people and central Government. Co-ordination between Departments on matters affecting disabled people has also benefitted significantly from the appointment.

Sunningdale Seminar on Disablement

The Sunningdale Seminar on Disablement held in February 1976 was a unique occasion which brought together a wise diversity of interests to discuss the whole range of problems facing disabled people. A report of the proceedings, reflecting the wide range of views expressed, has been widely circulated. Many of the suggestions put forward have been considered by Departments and a discussion document which examines these suggestions is shortly to be circulated for comment to statutory and voluntary agencies, to all who attended the Seminar, and to other interested invididuals and organisations.

UN Declaration of the Rights of Handicapped People

This declaration which was co-sponsored by the UK set out the basic rights of disabled people to appropriate treatment and care.

UK Co-sponsors UN Declaration of 1981 as an International Year for Disabled Persons

Statutory and voluntary agencies will be involved in national and international events designed to realize the Year's theme of 'full participation'. A significant event during the Year will be the adoption by the United Nations of a programme of action to promote the rights of disabled people and improve the special provisions made for them. In addition, a World Planning Group established by Rehabilitation International, under the chairmanship of Mr Morris, is preparing a "Charter for the 80's" which will set out priorities for planning and action on the prevention of disability and on rehabilitation. It is intended that this work should compliment the preparation of the United Nations document.

Approaches to Non-Government Organisations

In support of the Silver Jubilee Campaign on Improving Access for Disabled People, the emphasis of whose campaign has been on increasing public awareness of the access difficulties met by disabled people, the Minister for the Disabled has written to a number of important non-government organisations, reminding them of the importance of catering for disabled people's needs and suggesting possible further ways of so doing. The organisations approached include: the Retail Consortium; the Association of British Travel Trust agents; the British Hotels, Restaurants and Caterers Association, British Rail; British Gas, the Electricity Council; and the four principal clearing banks. Initial responses to the Minister's letter have been positive and encouraging.

DHSS/Post Office Liaison Committee

The Committee was established to facilitate an exchange of information over the whole field of telecommunication aids for handicapped people. It enables DHSS to advise the Post Office of the requirements of handicapped persons, and the Post Office to advise DHSS of technical developments and possibilities to meet these requirements. It is open to the Committee to co-opt people from other Departments and organisations as necessary.

The decision to set up this Committee was taken in February 1974 and the first meeting was held on 30 September 1974. Work is in hand to assess the use of a variety of aids developed by the Post Office to help disabled people to use the telephone.

Personal Social Services Council New Group on People with Handicaps

In November 1976 the Council set up a new group on "People with Handicaps" after consultation with organisations and individuals in the field of disability, in connection with the Council's responsibility as successor to the Advisory Committee on the Health and Welfare of the Disabled.

The Group's terms of reference are:

> "to keep under continual review all matters affecting the needs of those people with handicaps to whom the provisions of the Chronically Sick and Disabled Persons Act 1970 apply; to be available for consultation by Ministers or by any interested organisation or group whether statutory, voluntary or professional; to establish and maintain contact with such bodies and to ensure that their views are taken into account by the Council; to draw widely on experience or advice from any appropriate source; to encourage or promote enquiry or study; to advise the Council and, where appropriate, to take action on its behalf."

Current membership of the group is: Mr Walter Boyce (Chairman), Director of Social Services, Essex County Council; Councillor Phillip Bolshaw, Chairman, Hertfordshire Social Services Committee; Mr A M Wood, Vice-Chairman, Wales Council for the Disabled; Dr Brian Meredith-Davies, Director of Social Services, Liverpool Metropolitan District Council; and Councillor D Blunkett, Sheffield Metropolitan District Council. The group also includes a nominee from the Department's Social Work Service and a senior DHSS administrator.

Phasing-in of the Behind-the-Ear Hearing Aid

A new behind-the-ear aid became available in November 1974 free-of-charge through the National Health Service both to new patients and to those who wished to exchange their old body-worn aid. Up to about one million people may be eligible for the new aid and a system of priorities was introduced. From 1 September 1975 the scheme was extended to include people of any age normally in employment, or receiving education and from November 1977 all deaf people became eligible for the new aid. By the middle of 1977 about 400,000 of these aids had been issued.

Special Hearing Aids for Children and Young People

On transfer of the School Health Service to the National Health Service on 1 April 1974, Area Health Authorities became responsible for providing special hearing aids available commercially to those children for whom they were recommended on medical grounds. The Government recognised that the educational, social and emotional development of the severely deaf child and adolescent is slow and extended the age limit previously applied under the Local Education Authority Scheme, from 16 years (19 years if continuing in education) to 18 years (21 years if in full-time education).

Advisory Committees on Hearing Impairment

Specialist advice on the needs of the hearing impaired has always been available to the Secretary of State for Social Services through an advisory panel. However, services for the deaf had developed to such an extent since the panel was set up that its terms of reference had become inadequate. Because of the importance of the Department's work for the deaf it was decided to make an entirely fresh start through the establishment of two new Advisory Committees, one to look at health and personal social services for the hearing impaired, and the other to consider matters related to equipment. Four reports have been produced so far: on adult rehabilitation, the role of audiological scientists, services for children and the role of Social Services. The reports have been commended to health and local authorities.

Institute of Hearing Research

Section 24 of the Chronically Sick and Disabled Persons Act required the Secretary of State for Social Services to collate and present evidence to the Medical Research Council on the need for an Institute of Hearing Research. As a result the Government announced that it proposed to establish an Institute of Hearing Research and Dr Mark Haggard was appointed Director on 1 January 1977. The Headquarters of the Institute is at present located in the Medical Science Building at Nottingham University. An ad hoc working group has been set up by DHSS and MRC to consider possible locations for outstations studies. The first out-station in England will be located at the Royal South Hants hospital, Southampton. In Wales and Scotland out-stations have been approved in Cardiff and Glasgow respectively.

Audiological Medicine - A New Specialty

The Government (and its predecessor) recognised the need for a new medical specialty which will be concerned with the medical and rehabilitation aspects of deafness and vestibular disorder of any degree and at any age, rather than with the surgical aspects of ENT. Following discussions with the Royal College of Physicians and Royal College of Surgeons, it was agreed that a new specialty in audiological medicine should be created, and details of the training requirements have been sent to Post Graduate Deans.

Development of Audiology Services

In view of the urgent need to develop services for the deaf the Government made an additional £½ million available to National Health Service Authorities over the three-year period 1974/76 to 1976/77 for defined capital and revenue projects. Subsequently, the additional revenue allocations were built into regional allocations on a recurring basis. These special funds, which were partly matched by allocations from Regional funds, are being used to meet the demands of the audiology services to provide additional technicians, equipment and improvements in accommodation at Hearing Aid Centres and for technicians' training courses.

Co-ordination with DES

At the request of that Department, a Sub-Committee of the DHSS Advisory Committee on Audiological Equipment has been set up to provide advice on the method of maintaining audiological equipment in schools in a fully effective condition. This Sub-Committee will be producing a report shortly.

Guidance for Hearing Aid Users

A booklet entitled "General Guidance to Hearing Aid Users" has been published by the Department and is issued free of charge to anyone who wears an NHS hearing aid. A revised illustrated version of the booklet was made available in March 1977. The publication is also of use to anyone coming into contact with a hearing impaired person and has been given wide distribution throughout the health and personal social services.

Updating of NHS Hearing Aids

In August 1978 a new NHS high-power body-worn hearing aid (code no BW61), representative of modern technology, is being introduced to replace the existing Medresco models OL58, OL58c, and OL63. In 1979 a new high-power earphone will extend the fitting range of the new aid to include some people who at present are not suited by the standard range.

Hospital ENT Services "Design Guide"

A Hospital ENT Services "Design Guide" was issued to hospital authorities in March 1974. This deals with the facilities required at a district general hospital for out-patient treatment and for an associated hearing aid centre. Central funds totalling £300,000 have been allocated for two new centres to be built in order to evaluate and test the Design Guide's standards. Building work at Withington Hospital, Manchester, should be completed in 1979/80 and at the Derbyshire Royal Infirmary, Derby, in 1978/79.

Hearing Therapists

Arising out of a report of the Advisory Committee on Services for Hearing Impaired People the Government have made special funds available over a four-year period to enable health authorities to establish two or three posts for hearing therapists. The first one year training course is due to commence at the City Literary Institute in September 1978.

Staff Training on Deafness

With the object of promoting awareness of the special communication problems and needs of adults with acquired deafness the Social Work Services of the DHSS and Welsh Office have produced a staff development training package for use in social services departments. The material can be easily adapted for use by health authorities.

VISUAL IMPAIRMENT

Increase in Blind Persons Tax Allowance

The special tax allowance for the blind was increased from £130 per annum to £180 per annum following an announcement by the Chancellor in his budget speech on 12 November 1974.

Capital grants promised for pilot residential units for deaf-blind adolescents and young people

Because of the, fortunately, small numbers of people who are both deaf and blind, it is difficult to make arrangements locally for appropriate training and, if necessary, accommodation. The problem has become more acute as the children handicapped as a result of the rubella outbreaks of the 1950s and 60s reach adolescence and adulthood. Many of them would benefit from a period of further training to follow their formal education.

In discussions with the four voluntary organisations principally concerned - the Royal National Institute for the Blind, the Royal National Institute for the Deaf, the National Association for Deaf-Blind and Rubella Handicapped and the National Deaf-Blind Helpers' League, it was agreed that two experimental residential units should be established. The Department promised substantial capital grants towards these. Construction work should begin in 1978 on a purpose-built centre at Poolemead, near Bath, to be run by the RNID. The other centre will be run by the National Association of Deaf-Blind and Rubella Handicapped, based on existing, but suitably adapted property at Market Deeping, near Peterborough. It is hoped that this Centre will become operational during 1978.

New NHS Optical Arrangements

The Government has introduced a broadly flat-rate system of charges (in place of cost-related charges) payable by patients supplied with spectacle lenses under the National Health Service. This means that people will pay the same for a particular type of lens irrespective of the strength required.

The Government has extended the categories of children and young persons who are excepted from the liability to pay certain charges for the replacement and repair of optical appliances to include those attending any school within the meaning of the Education Act 1944 or the Education (Scotland) Act 1962 and all children under 16.

The decision to exempt the registered blind and partially sighted from NHS optical charges altogether will be implemented as soon as suitable legislation can be introduced.

Where a patient suffers from photosensitive epilepsy and has no significant refractive error, polarised glasses can be prescribed under the Hospital Service by the consultant in charge of his treatment and there will be no charge to the patient.

Spare pairs of glasses may be prescribed under the Hospital Eye Service by a consultant ophthalmologist where in his opinion they are necessary for the benefit of the patient. In such cases the spare glasses will be subject to the same charge, if any, as the first pair.

Safety lenses in glasses may be supplied under the National Health Service without extra charge where they are prescribed as clinically necessary under the Hospital Eye Service.

Low vision aids can be prescribed under the National Health Service through the Hospital Eye Service and issued on loan without charge for as long as patients require them. Where a partially sighted person feels that such an optical appliance may benefit him, it is open to him to discuss the matter with his family doctor with a view to referral to a hospital for consideration of his problem.

British Rail agree to admit guide-dogs to sleeping cars

Under a new scheme introduced by British Rail, a blind passenger with a guide dog may travel in a first-class sleeping compartment and be charged only the second-class fare. Previously, blind people were separated from their guide dogs. The dogs were kept in the guard's van.

MENTAL HANDICAP

National Development Group for Mentally Handicapped

The National Development Group was set up in 1975 to advise the Secretary of State and play an active role in the development of Departmental policy for the mentally handicapped and the strategy for its implementation. The Chairman is Professor Peter Mittler, Director of the Hester Adrian Research Centre for the Study of the Learning Processes in the Mentally Handicapped, University of Manchester. The Group has produced five pamphlets on different aspects of mental handicap services.

Development Team for the Mentally Handicapped

At the same time a separate Development Team was formed. Its main task is to encourage and advise on the implementation of national policy at all levels. The Team works in partnership with field authorities, with the aim of improving services and making better use of resources. The Director of the Team is Dr G B Simon, Medical Director of Lea and Lea Castle Hospitals and Director of the Institute of Mental Subnormality, Kidderminster.

Programme Planning Group on Mental Disorder

A Programme Planning Group on Mental Disorder was set up in 1975 jointly by the Scottish Health Service Planning Council and the Advisory Council on Social Work. The Group is reviewing current policies relating to the provision of health, social work and related services for the mentally disordered, covering both the mentally ill and the mentally handicapped. The Programme Planning Group was constituted on the basis that, following upon the submission of initial reports to the Council, it would make recommendations from time to time either to the Council or to the Scottish Home and Health Department in the light of ongoing developments in its area of concern. In general, Programme Planning Groups are seen as vehicles for long term planning. They are intended to explore the needs of identifiable health care groups which are not the domain of one particular profession, or of one particular branch of the service and which are also likely to involve health related services like social work, housing, employment and education. A sub-committee on Mental Handicap has already produced an interim report drawing attention to the features of mental handicap services requiring urgent attention.

Jay Committee .

A Committee of Enquiry was set up in 1975, under the chairmanship of Mrs Peggy Jay to examine the nursing and care of the mentally handicapped. Its recommendations will have a significant effect on the work and training of staff in mental handicap institutions run by both the health service and local authorities, as well as the care of mentally handicapped people themselves.

AIDS

Assessment of Aids and Equipment

The full scale research studies carried out under the auspices of the Reseach Liaison Group are necessarily costly, lengthy, complex undertakings. Therefore a need has been recognised for less elaborate professional assessment to be carried out at Rehabilitation Centres and for the results to be published. A small Advisory Panel, consisting of representatives of various specialities, and of the DHSS has been set up to consider the assessment proposals put forward by the Centres.

Environmental Control Aids

The Department provides, through RHAs, environmental control equipment which enables even the most severely disabled people to operate a number of domestic appliances including lights, radios etc. It can be operated either by breath suction, the flick of a finger or other slight movement. The original range of aids has been expanded by the addition of PSU3; the additional facilities which this provides include the ability to operate a telephone and control television sets. More typewriter controls have also been made available for non-communicant disabled people.

The Possum Users Association, a voluntary organisation run by users of environmental control equipment for other users, has for some years provided typewriter control equipment for loan to terminally ill patients. The Department has made available to the Association some refurbished units to enable them to expand their activities in this area.

Advisory Group on Medical and Scientific Equipment and Aids for the Physically Disabled

The Advisory Group on Medical and Scientific Equipment and Aids and Equipment for the Disabled has been set up in Scotland inter alia replacing the Equipment Research Committee and the Scottish Standing Committee on Prosthetics and Orthotics. Its terms of reference are:

> "Having regard to the advice of the Chief Scientist on Research and Development needs generally within the Health Service, to advise the Health Service, to advise the Planning Council on the requirements for and on the use of medical and scientific equipment and aids for the physically disabled in the Health Service including research, development and evaluation in relation to the prosthetic and orthotic services."

The Group has three Committees on, respectively, Equipment Research and Development, Equipment Evaluation, and Prosthetics and Orthotics.

Development and general introduction of cosmetic calipers for NHS patients

Several types of cosmetic caliper are now available for supply through the NHS. These include the Stanmore caliper developed by the Institute of Orthopaedics, Royal National Orthopaedic Hospital and the Salford caliper developed by the Salford Royal Hospital and University of Salford in conjunction with the Department.

Improvements in wheelchair service

i. Wheelchair users are provided with a booklet "Hints on the use of your wheelchair". In 1977 the main user booklet for self-propelled wheelchairs was substantially improved and enlarged. This was followed in 1978 by a much improved booklet for the pushchair and other booklets are in course of upgrading.

ii. Proportional control enables a powered wheelchair to accelerate smoothly. These controls are now being provided for users who have injuries or conditions in which sudden or jerky movement would exacerbate the injuries.

iii. Wheelchair design is constantly reviewed and recent improvements include the introduction of a child's model with rigid seat and backrest to give more support, the introduction of a model with foot steering and the provision of moulded seat inserts.

iv. Quick delivery depends on availability of wheelchairs throughout the country. The number and variety of wheelchairs held in local stocks have been increased. Stocks of components and spare parts to effect speedy repairs have also been introduced at local centres.

Review of wheelchair service

A review was announced by the Minister for the Disabled on 6 February 1978 of the Department's arrangements for the recommendation, prescription, supply, repair and maintenance of wheelchairs. Interested organisations are being consulted and representative wheelchair users are assisting with the review. Completion is expected early 1979.

Working Group on patient support systems

The search for improved patient support systems and surfaces continues to demand the attention of people concerned with the problem of pressure sores. Research and evaluation projects have been supported by DHSS and the Department has set up an internal working group to examine new proposals and methods of evaluation.

Stairlifts and Personal Passenger Vertical Lifts for the Disabled

Following reports of accidents and of the unreliability of some of the stairlifts and vertical lifts for disabled people installed mainly by local authorities or privately, the DHSS sponsored a technical survey of stairlifts currently available and a sample survey of the numbers issued by local authorities and their experience of their use. A technical survey of vertical lifts is being undertaken.

Study of Aids to Daily Living

Most disabled people need some special aids or equipment to help them in their daily life. They are faced with a bewildering variety of commercially produced items and often find it difficult to obtain impartial advice or information on what would best suit their needs. The Department of Health and Social Security has therefore commissioned the Institute for Consumer Ergonomics at Loughborough to carry out a study of aids to personal hygiene - and Edinburgh University to carry out a study of patient lifters. The results, when available, will be of international importance.

MOBILITY AND TRANSPORT

Extension of Orange Badge Parking Scheme

The Orange Badge Scheme was introduced in December 1971 by Regulations made under the Chronically Sick and Disabled Persons Act 1970. It was extended on 1 June 1975. Badge holders, who now include blind people registered under the National Assistance Act 1948, may leave vehicles displaying the badge, without charge or time limit at parking meters and without time limit where limited waiting otherwise applies. Additionally in England and Wales vehicles may be left for up to two hours on yellow lines of all kinds, except when there is a ban on loading or unloading in force, or in a bus lane and provided a special orange parking disc is displayed. In Scotland, where there is no time limit on waiting on yellow lines the situation remains unchanged except that parking is not allowed when there is a ban on loading or unloading in force, or in a bus lane.

The scheme applies throughout Great Britain, except for a small area of central London: the Cities of London and Westminster, the Royal London Borough of Kensington and Chelsea and part of the London Borough of Camden. These four boroughs issue orange badges for use elsewhere and operate their own local badge schemes but only for disabled people resident or working in the borough.

Petrol allowances

From 1 January 1975 all drivers of DHSS-supplied invalid tricycles or cars became entitled to an allowance of £10 per annum to compensate them for the increase in VAT on petrol. Some who get this new benefit already had a £5 per annum petrol allowance as a preserved right from an earlier scheme; this has been merged into the new allowance.

Financial and administrative support for major new voluntary organisation: Motability

An important new voluntary organisations: "Motability" has recently come into being. It aims to help disabled people in receipt of mobility allowance to obtain and run suitable cars either as drivers or as passengers when they are unable to drive themselves. The Government are providing practical administrative support for the organisation, including a grant towards expenses and are watching its development with close interest. By the end of 1979 it is estimated that mobility allowance will be payable to 100,000 new beneficiaries and possibly 25,000 ex-vehicle scheme beneficiaries who will be able to spend their allowance with Motability if they so wish.

Exemption from Vehicle Excise Duty

From 1 December 1978 exemption from vehicle excise duty will be available to Mobility Allowance beneficiaries or persons appointed by the Secretary of State to act for them, or to persons they have nominated instead. The Department of Health and Social Security will write to all beneficiaries (and persons appointed to act for them) enclosing a form on which to apply for a certificate for claiming exemption from payment of vehicle excise duty and, on receipt of a valid application, will issue such a certificate. The Department of Transport (through its local vehicle licensing offices) may grant

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exemption on the production of this certificate provided the vehicle is used by, or for the purposes of, the Mobility Allowance beneficiary. Only one exemption may be granted in respect of any beneficiary.

Exemption for certain disabled people from statutory restrictions on car hire-purchase and rental or leasing times

Disabled people who get a mobility allowance because they are unable or virtually unable to walk are now able to buy standard cars exempt from control. The Hire Purchase Orders already exempted vehicles specially constructed or adapted for disabled people, but not the sale of other cars to severely disabled people. The amending order, which came into force on 18 December 1975 exempted from control from 1 January 1976 vehicles supplied under a Hire Purchase or Credit Sale Agreement to a hirer or purchaser who was:

a. A person entitled at the time the agreement was made to a mobility allowance under Section 37a of the Social Security Act 1975;

b. A Receiver appointed by the Court of Protection (or in Scotland tutor, curator or other guardian) with power to act for a person falling within (a);

c. A person appointed by the Secretary of State under the Social Security (Claims and Payments) Regulations 1975 and the Mobility Allowance Regulations 1975 to act for a person falling within (a);

d. A person nominated by any person referred to in (a) and (c) above;

provided that such hirer or purchaser had not already obtained a vehicle by virtue of the above provisions under an agreement which was still subsisting. Holders of mobility allowances may apply to the Department of Health and Social Security for a certificate that will confirm their eligibility.

These concessions have been extended to beneficiaries of the former invalid vehicle scheme with effect from 1 June 1977 and, from the same date, special terms for the long-term hire of a vehicle have been available to both mobility allowance and former invalid vehicle scheme beneficiaries.

Motorway service areas

All motorway service areas in England now provide basic facilities - lifts, ramps, reserved parking bays and special toilet facilities - for disabled people and this fact will be indicated by the display of the disabled symbol and the words "facilities for the disabled" on the half mile services sign either side of the service area.

Tolled Crossings

Most tolled crossings in England grant exemption or waive tolls for drivers of vehicles exempt from excise duty under Section 6 of the Vehicles (Excise) Act 1962 or Section 11 of the Finance Act 1964. In November 1973, the Department of the Environment proposed that exemption from tolls should be extended to all vehicles carrying disabled people which displayed an Orange Badge. These proposals were implemented at the Department's Severn Bridge with effect from 24 May 1974 and in Scotland by order of the Secretary of State for Scotland at the Forth and Tay Road Bridges with effect from 20 November 1974 and at the Erskine Bridge with effect from 11 December 1974.

Disabled Drivers as Supervisers of 'L' Drivers

Legislation has been enacted to allow drivers with leg disabilities to put their driving experience at the disposal of those who are learning to drive. Such drivers will be able to supervise 'L' drivers in cars if they are fully licensed to drive cars with the same sort of transmission whether or not their licenses are subject to restrictions.

Traffic Signs

Two distinctive signs incorporating the disabled person symbol and showing special facilities have been prescribed. One is a direction sign to toilets which include facilities for disabled people; the other is a parking (P) sign for parking places reserved for Orange Badge holders.

Supplementary plates reading "Except disabled badge holders" and incorporating the wheelchair symbol may now be fixed to signs indicating prohibitions on vehicular traffic.

Public Transport

British Railways, as a result of a DOE circular, have made, or are in the course of making, certain special arrangements for disabled travellers. They include assistance with car-parking near to stations, the provision of narrow wheel-chairs at principal stations for negotiating coach corridors; and at main stations marking routes for disabled people to gain easy access to platforms and providing 'call for aid' signs indicating where disabled travellers can obtain assistance.

At all new British Rail Stations, facilities for the disabled include ramp and special toilet facilities, with clearly visible pictograms to indicate their location. New rolling stock on several electrified lines is fitted with doors at platform level to facilitate entry for the disabled.

Registered disabled people in wheelchairs can travel in first-class coaches on Inter-City trains using the new Mark III coaches for half the ordinary adult second-class single fare; an accompanying attendant can also travel at the same reduced rate. Disabled passengers in wheelchairs and accompanying attendants who have to travel in the guard's van are each charged only half the second-class ordinary single fare.

The whole question of fares for disabled people is currently being examined by the British Railways Board.

Buses

The difficulty of getting on and off buses is a major cause of concern for disabled people. By amending Public Service Vehicles (Conditions of Fitness, Equipment and Use) Regulations to remove the requirement for a minimum step height the Government have enabled bus operators and manufacturers to incorporate the lowest step height possible in future design of buses.

Concessionary Bus Fares

Local authorities have powers under S138 of the Transport Act 1968 to provide travel concessions for blind and disabled people. A Department of Transport Circular, which dealt with concessionary fares generally, recommended that all local authorities should aim for a minimum standard of a half-fare concession for blind and disabled people, which should be available at peak as well as off-peak periods. It recommended also that wherever possible guide dogs and invalid chairs should be carried free and that local authorities should bear in mind the need of many handicapped people to be escorted when travelling.

London Transport

London Transport commissioned an independent survey into ways in which travel on the Underground could be made easier for the disabled. Proposals are in hand to implement some of the recommendations resulting from the survey. London Transport stress however, that they do not consider the underground suitable for the seriously disabled.

London Transport have already adopted certain measures to assist the disabled using their services; eg the new bus fleet of double deck buses now on order will have more handrails and lower steps to facilitate easier boarding and notices have been put up at stations, bus shelters and on buses and Underground trains asking people to give up their seats if required by a disabled person. In addition, the London Boroughs have agree to pay for permits for the disabled which entitle them to free bus travel outside the rush hours. Holders of these permits are also allowed cheap rate travel on the Underground outside the rush hours. Blind people are, at all times eligible for free travel on the buses and subject to a maximum fare on the Underground.

Research study of the needs of disabled drivers and passengers

With the eventual need to provide for those among the existing three-wheeler drivers who will still need a specialised vehicle when their three-wheeler can no longer be replaced and the need to encourage developments which could lead to a better choice of specialised vehicles or adaptations to production cars becoming commercially available to disabled people generally, the DHSS and the Department of Transport have considered what further research was desirable to pick out and encourage among the many possible lines of development those which have the best prospects of effectively meeting the needs of disabled people. They are now mounting a research study through the Motor Industry Research Association of the extent to which the diverse needs of disabled drivers and passengers can be met by available adaptions to ordinary motor cars and of the potential value of further adaptions or specialised vehicles which are available or under development.

EDUCATION

Section 10 of Education Act 1976

Section 10 of the Education Act 1976 sets out the requirement that - from a date to be named by the Secretary of State - handicapped children are to be educated in ordinary schools unless this would be impracticable, incompatible with the efficiency of the ordinary school, or involve unreasonable public expenditure. A large number of organisations concerned with special education were consulted in 1976 but no action will be taken until the Report of the Warnock Committee has been considered (see page 21).

Warnock Committee

A Committee of Enquiry was established in September 1974 under the chairmanship of Mrs Mary Warnock to review educational provision for handicapped children and young people in England, Scotland and Wales.

Its report, entitled "Special Education Needs" (Cmnd 7212) was published on 24 May, 1978 and is available from HM Stationery Office, price £5.65. A popular version of the Warnock Report entitled 'Meeting Special Educational Needs' has been published by HMSO at 85p, and this is intended particularly for parents of handicapped children and others with an interest in the Report. The Department of Education and Science, the Department of Health and Social Security, the Department of Employment and the Welsh Office are consulting a wide variety of organisations with an interest in special education on the Report's recommendations and anyone who wishes to do so may ask to be consulted. Apart from making recommendations touching on the aspects of the education and training of handicapped children and young people, the Warnock Committee commissioned various research projects, including a review of recent research in special education, which is also expected to be published shortly.

Provision for the needs of Disabled People in Educational Establishments

Following an undertaking given by the Government during the report stage of the Education Bill on 29 October 1976, the Department of Education and Science issued a circular letter in January 1977 to local Education Authorities asking them to indicate in any plans submitted to the Department for schools and further educational establishments the provision they proposed to make for disabled people.

Survey of Further Education

Her Majesty's Inspectorate have surveyed arrangements by institutions of Further Education and other Local Education Authority services for formal and informal education, training and leisure activities for the handicapped. This includes special provision or support by Local Education Authorities and placement of students by them in provision made by voluntary organisations. The results of this survey have been made available to the Warnock Committee.

Guidance on Discovery of Children Requiring Special Education

The Department of Education and Science and the Welsh Office issued a circular of guidance to local education authorities in March 1975 which contained a fresh statement of what was involved in discovering which children require special education and what form it should take. The circular sought to clear up uncertainties and confusion concerning the subject of ascertainment, and examined the three stages of discovery, diagnosis and assessment. Stress was laid on informality and on involving parents at all stages; and the balance between educational and medical responsibilities was clarified. An improved series of forms was introduced for recording the educational, medical and psychological data required for deciding a handicapped child's needs for special education.

EMPLOYMENT: REHABILITATION, TRAINING AND JOB OPPORTUNITIES

"Positive Policies" - A Guide to Employers

An important ESA priority over the next few years will be to increase the orientation of the disablement resettlement service towards employers, with a view to securing improved voluntary co-operation by employers in providing more and better job opportunities for disabled people. A new Employers' Guide on the employment of disabled people - "Positive Policies" - was published, jointly by MSC and the National Advisory Council, in late Spring 1977. The Guide is being used by the Disablement Resettlement Service as the starting point in a concentrated programme of visits to, and other contacts with, employers, with the aim of persuading them to develop proper management policies covering all aspects of the employment of disabled people (including recruitment, training, career development, and promotion).

Revised assistance with fares to work scheme

The MSC operate a scheme whereby severely disabled people who are unable to travel to work by public transport because of their disability can receive financial assistance towards the cost of their fares. The revised scheme, which comes into effect on 5 July 1978, has been simplified and the "means test" criteria has been removed.

Job Introduction Scheme

This scheme is designed to encourage employers to give certain disabled people a trial period of employment, during which they would have the opportunity of proving their capabilities to do the job. The length of the trial would be variable according to the individual circumstances, but in the majority of cases will be six weeks. Employers receive a contribution of £30 per week towards the wages of those they employ for the duration of the trial. The scheme is selective and designed to help those disabled people who might benefit most and for whom there is a prima facie prospect of the job becoming permanent.

Employment of Disabled People

In December 1975, following a three year review of policies and services for disabled people, the Government announced that the quota scheme and existing sheltered employment arrangements would continue in their present form, but the Department of Employment's former responsibilities in this field would be transferred to the Manpower Services Commission on 1 July 1976. The Commission, which is thus now responsible for all employment activities relating to disabled people (disabled young people may also use the Careers Service), wish to develop a unified and coherent employment policy aimed at helping disabled people to choose, train for and get the right jobs.

The MSC's programme for developing employment and training services for disabled people over the next 5 to 10 years was published in February 1978. The broad aim of the Programme is to improve and extend the existing services to disabled people rather than to develop new ones.

The development programme also announced the Commission's policies in the field of sheltered employment. The National Advisory Council's recommendations on priority supplier arrangements have been accepted by the Commission and discussions on their implementation are still going on. The Sheltered Employment Consultative Group held its inaugural meeting in January 1978 and has already a full agenda for each quarterly meeting. Other important matters to which the MSC is giving attention include the establishment of more enclaves (or sheltered industrial groups), the improvement of facilities for mentally disabled people and the continued integration of blind and sighted employees in workshops. A working part of the National Advisory Council will shortly commence a study of the wages structure in sheltered workshops.

The MSC is responsible for the provision of training facilities under the Training Opportunities Scheme (TOPS). Whilst TOPS applies to able-bodied and disabled people who require training for employment under ordinary conditions, the latter may, in addition, benefit from special training arrangements. The special arrangements may include vocational courses over one year in length (the maximum period available under TOPS), and vocational training courses at residential training colleges run by voluntary organisations who cater for more severely disabled people. In addition, individual training courses may be arranged with employers who are willing to provide employment after the period of financial assistance provided by the MSC.

HOUSING

Guidance on Housing Needs

The Department of the Environment, in association with the Department of Health, has been continuing its study of the housing needs of disabled people. Two circulars, one giving general guidance and the other advice on costs and space standards in new housing, have been issued. In addition two design guides have been published, one on Mobility housing, the other on Wheelchair housing. Mobility housing, which is ordinary housing designed so that it is convenient for the majority of handicapped people to live in, is a new concept. Each mobility housing unit planned will be entitled to an addition subsidisable allowance of £60. For wheelchair housing (which

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is special housing for disabled people) there is a new two-stage procedure; in addition to general allowances which can be claimed on top of the basic housing yardstick, there is the possibility of supplementary subsidised provision being incorporated when tenancies are allocated.

With regard to housing in the private sector, the Housing Act 1974 provides for grant aid for improvements to a disabled person's dwelling. An improvement grant may be given, at the discretion of the local authority, to cover works required for making a dwelling suitable for the accommodation, welfare or employment of a disabled occupant where the existing dwelling is inadequate for these purposes. Similarly an intermediate grant may be given for the provision of one or more standard amenities which, although not missing, are inaccessible because of the occupant's disabilities. A grant may also be made for roof insulation for a disabled person suffering hardship. Applications for grants are subject to the terms and conditions set out in the Act, one of which provides that applications may not be entertained in respect of a dwelling built since 2 October 1961. Under the direction in a recent circular, however, this date will not apply in relation to dwellings occupied by disabled persons.

In recognition of the part which adaptations to existing dwellings play in meeting the particular needs of disabled people, both in terms of increasing the provision of suitable housing and in enabling them to remain in familiar surrounds, the Department of the Environment, with DHSS and Welsh Office, has produced a consultation paper with a view to clarifying the respective roles of housing and social services authorities. The paper which is concerned with adaptations to housing in both the public and private sectors, has been sent to the local authority associations and the principal voluntary bodies in this field. The comments received have been analysed and guidance will be issued in August.

The Government recognises that progress in the field of housing for disabled people has been slow since the passing of the 1970 Chronically Sick and Disabled Persons Act. The Minister for housing announced on 4 February 1975 that he was starting an urgent drive to speed up the provision of suitable housing by housing authorities, new town corporations and housing associations and that within 12 months he aimed to have every housing authority in the country incorporating housing for disabled people in at least one new scheme.

The response to the drive was reported by the Minister in written answers to Parliamentary Questions on 14 April 1976 and 20 July 1977. These indicated that the progress made in starting and completing wheelchair and mobility units is encouraging but that more remains to be done.

In a circular issued by the Scottish Development Department in May 1975, local authorities were asked to accord a high priority to the provision of housing for physically handicapped people and, in particular, it was strongly recommended that they should include some houses for such people in any sizeable housing development. Guidance on the assessment of housing needs offered to Scottish local authorities in October 1975 stressed the need for particular attention to be given to groups, including physically handicapped people, who might have specialised housing needs. A similar point was made in the Consultative Document "New Towns in Scotland" issued in February 1975. Comprehensive advice on the assessment of housing needs is contained in Part I of the Scottish Housing Handbook, 'Assessing Housing Needs - A Manual of Guidance', published in 1977 and issued to local authorities in Scotland on 21 July 1977.

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Awards for Good Housing for Disabled People

In 1975 the DOE annual housing award scheme was extended to include a category of housing schemes containing units specially designed for disabled people. This has now become an established feature of the awards scheme, and in 1978 schemes containing mobility units became eligible as well as those with wheelchair units. Administration is by a national jury comprising people who have a special knowledge of the housing needs of disabled people.

Rating (Disabled Persons) Act 1978

New laws governing the payment of rate relief to disabled people were given Royal Assent on 21 July 1978.

The Rating (Disabled Persons) Act 1978 clarifies the circumstances in which rate relief on property is available; it provides for relief to be given in the form of a rate rebate; it specifies for certain facilities the amount of relief to be paid, and extends the type of institutions which are eligible.

Rate relief is currently paid to the disabled under obscure provisions of the General Rate Act 1967. These are now repealed.

The new Act's main purpose is to clarify the circumstances in which relief is available both to occupants of private dwellings and to institutions. It provides for relief to be given in the form of a deduction from the rate bill, rather than as a deduction from the rateable value as at present.

The Act specifies that in England and Wales, standard amounts are to be rebated from rate bills for certain facilities required for meeting the needs of a disabled person. Standard deductions include, for the use of each room, a sum equal to the rates that would be chargeable on a rateable value of £30, on a bathroom £20, on a lavatory £10, on floorspace for the use of a wheelchair £30, on a garage £25 or as assessed, on a carport £15, and on land for parking a vehicle £5. Deductions for heating appliances and other facilities will be subject to individual assessment by District Valuers.

A new statutory definition of institutions which may qualify for relief is contained in the Act, so that most institutions caring for the disabled are now covered.

The Act, which comes into force on 1 April 1979, originated as a Private Members Bill introduced by Mr Robert Hughes MP (Aberdeen North) and had full Government support. The Department of the Environment will be issuing advice about the administrative arrangements for the new scheme and the way in which relief should be applied for.

Housing in New Towns

NT Circular No 445, issued on 29 April 1976 to new town development corporations serving London, set out new guidelines for tenancy allocation, asked all corporations to review their present policies, and stress the need for adequate provision to be made for the elderly, the physically or mentally handicapped, and the seriously disadvantaged. The appendix to the circular also pointed out that housing for disabled people required special consideration, and suggested further provision of 'mobility' housing and specially designed units, with the necessary support services provided by the Social Services and Health Authority. NT Circular No 466, issued on 17 November 1976, subsequently commended the policies set out in NT Circular 455 to the remaining new towns. Annual discussions are now being held with each new town development corporation to establish, within the overall allocation of tenancies which they expect to be able to make available during the following year, the contribution which the new town can make to housing people in these special categories. In addition the forthcoming DOE guidance on house adaptations in the local authority sector will apply to those development corporations whose main housing stock has not been transferred to a local authority.

Promotion of EEC-Funded Study of Housing and Care for Disabled People

In August 1977 it was announced that an EEC grant of £100,000 was being channelled through the Department of the Environment for a three year contract to study housing and care for disabled people. The programme of work is being undertaken by the Crossroads Care Attendant Scheme Trust, with a focus on four local authorities in England and one in Scotland, the aim being to examine the housing needs of severely handicapped people (for new wheelchair or mobility housing or house adaptations) in relation to domiciliary care services of the kind being developed by the Crossroads Trust. The DHSS has undertaken to share with the social services department the costs of care attendant schemes set up in the four English areas. The Crossroads Trust is at the same time co-operating in the development of local care schemes in other parts of the UK.

ACCESS AND DESIGNING FOR DISABLED PEOPLE

Silver Jubilee Access Committee

The Silver Jubilee Access Committee was set up by Mr Alfred Morris MP, Minister for the Disabled, in June 1977, to harness, for the benefit of disabled people, the goodwill created by the Silver Jubilee celebrations. Its terms of reference are:

> "To consider ways of ensuring that disabled people can use and move about within the environment, inside and outside; to recommend changes to those responsible; and to consider ways of altering public attitudes in favour of the Committee's aims."

Amongst the initiatives pursued by the Committee in the course of its year-long campaign were: an award scheme to recognise valuable local initiatives; a competition for school-children of all ages; a short technical film for architects and planners; and a survey of accessible cinemas and theatres in England, Scotland and Wales. The Committee's campaign culminated in a National Access Week (4-10 June 1978), when local events were organised throughout the country and the awards and schools competition prizes were presented in London by HRH the Duchess of Kent. The Committee is preparing a report on its activities.

Awards for Best Building for Disabled People

The Minister for the Disabled presented the awards at an exhibition at the RIBA on 2 November 1976. The aim was to encourage the provision of facilities for disabled people in public buildings. It was hoped to give further impetus nationwide to the implementation of sections 4-8 of the Chronically Sick and Disabled Persons Act 1970.

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A similar scheme in Scotland attracted 51 nominations and awards were made to the owners and architects of the winning buildings on 8 November 1976. Likewise in Wales a similar scheme attracted 45 nominations and awards were made to the owners, architects and builders of the winning buildings by Parliamentary Under Secretary of State for Wales, Mr Barry Jones MP at a Presentation Dinner on 8 October 1976.

Technical Guidance on Designing Government Buildings to Meet Needs of Disabled People

New design guidance on the provision of facilities for disabled people in Government office buildings was issued in June 1978 as a Technical Instruction to PSA designers. An associated PSA circular requires that the provisions of the Instruction be incorporated in the design of all new office buildings and introduces a programme of adaptation work for the existing office estate. Introduction of the new provisions to existing buildings will necessarily be a gradual process but funds have been made available for the adaptation of at least one building in 56 locations as a matter of priority.

In parallel, the Welsh Office has published design guidance for the benefit of local authorities and designers outside PSA.

Access to Polling Stations

The two general elections in 1974 brought to light the difficulties in many areas for the disabled elector who wishes to cast his vote in person. In January 1975 the Home Office issued a circular which encouraged local authorities to review the arrangements at polling stations from the point of view of access for the disabled and suggested methods by which the problems facing the disabled elector could be overcome. The circular made it clear that the long-term objective should be to have every polling station capable of easy access by old and disabled people. Similar action has been taken by the Scottish Home and Health Department.

Access for Disabled People - Design Guide and Wallchart

The Welsh Office has produced an attractive, easy to follow guide to designing buildings taking special account of the needs of the disabled. It is aimed at architects, designers, planners and owners of all public buildings and is available, free, from Welsh Office Information Division, Oxford House, Hills Street, Cardiff CF1 2XG.

Standards for Ramps for Wheelchair Users and Others

Ramps for wheelchair users in buildings for which plans are approved after 1 December 1975, when the third amendment to the building Regulations 1970 came into force, must not have a slope of more than 1 in 12.

RESEARCH

DHSS Research Liaison Group

Considerable sums - hundreds of thousands of pounds a year - are now being spent by Government Departments on Research into the needs of disabled people. As part of a new mechanism to ensure a comprehensive examination of priorities in a scientific manner, the DHSS has established a number of Research

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Liaison Groups, one of which is specifically concerned with research in the field of physical handicap. The Group, on which civil servants and scientific advisers sit, is responsible for commissioning and stimulating research in areas identified as priorities. To date a considerable body of research on a wide range of questions has been commissioned.

MISCELLANEOUS

District Handicap Teams as recommended by the Court Report to provide a Multi-Disciplinary Framework within which all the needs of Severely Handicapped Children can be met

The Court Committee on Child Health Services reported in 1976, and among its recommendations was the establishment of District Handicap Teams. Following extensive consultation Ministers have accepted this in principle, and health and local authorities have been asked to establish such teams and to report on progress in the strategic plans which health authorities will be submitting early next year.

Our guidance envisages that each team will have a clearly definable core membership although membership and operational policies will be flexible and take account of local needs. District Handicap Teams will provide a framework within which all the needs of severely handicapped children can be met. They will have close links with appropriate voluntary groups, parents' organisations and will of course be available for consultation by professional staff concerned with the assessment and support of children with less severe and complex problems. We attach particular importance firstly to the fact that the team should provide a focus for specialist assessment and co-ordination of support for all children, irrespective of the nature of their handicap, and secondly to the team becoming a common service to health education and social services authorities. A joint approach by these three key services is essential to the care of the handicapped child.

VAT Zero-rating

The VAT (Aids for Disabled) Order came into force on 1 June 1974. It zero-rated for VAT the supply to chronically sick and disabled people of a wide range of medical and surgical appliances for domestic use if prescribed by a doctor and the supply of many aids to daily living (such as special beds, hoists and lifts, and sanitary aids).

It also zero-rated the supply to charities of wireless sets for free loan to the blind, and extended the zero-rating of "talking books" and associated equipment to any charity supplying this equipment to the blind or to other severely handicapped persons.

From 7 April 1976, a charity registered for the tax may recover the VAT it pays on wheelchairs and other essential aids purchased for loan, or hire at a nominal charge, to the disabled.

Dental Treatment for Handicapped Persons

In April 1978 (HC(78)14) the Secretary of State for Social Services gave health authorities direction to use any spare resources in their community dental services to treat adult handicapped patients who, by reason of their handicap, were unable to obtain routine dental care in the normal way.

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Remedial Professions

A co-ordinating committee set up in March 1975 to monitor action on the McMillan Report on the Remedial Professions completed its remit in November 1977. Among the developments stemming from its work have been:

> Centrally - funded management courses for senior therapists;
>
> Central finance for two research fellowships and for research appreciation courses for the remedial professions;
>
> the issue of new professional guidance on medical/remedial and nursing/remedial profession relationships;
>
> proposals for the future management arrangements for the remedial professions have been widely circulated to health authorities and other interested bodies, whose comments are being taken into account in a new circular of guidance now in preparation.

The Department has appointed two part-time advisers in remedial therapy, one an occupational therapist and one a physiotherapist who also advises on remedial gymnastics.

Following recommendations of the Quirk Report on Speech Therapy the Department has appointed a part-time adviser in speech therapy, and has given approval for the appointment of area speech therapists by health authorities. The number of training places for speech therapists have been increased to a level which already exceeds the Quirk Report target for 1982.

The 1975 Halsbury Report on the Professions Supplementary to Medicine, including the remedial professions, led to a number of wide-ranging improvements in pay structure and conditions of service for all the professions concerned, which have encouraged recruitment to the NHS and significantly improved the prospects for career progress.

Special action has been taken to increase the number of students undergoing training at physiotherapy and occupational therapy training schools so as to achieve faster rates of growth of these professions in the NHS.

Classification and Assessment of Impairment Disability and Handicap

A meeting, sponsored by the Department of Health and Social Security, between those concerned with developing systems of classification and assessment and those who need to use them was held at Alexander Fleming House, Elephant and Castle, in October 1976. The meeting considered the possibilities of various systems and the demands to be made on them. Following this meeting the Department has sponsored a research study to investigate and compare different systems of classification. The study is expected to be complete by September 1979.

Extension of Special Concessionary TV Licence Arrangements for People in Old People's Homes

As from 6 April 1978 more elderly people - including elderly disabled people - will have benefitted from the Old Person's Home concessionary TV Licence (price 5p). As from that date pensioners living in the specified accommodation are eligible if they have the services of a warden, resident or visiting, or enjoy some other form of communal facility associated with that accommodation.

Sport and Recreation

The Government's 1975 White Paper on Sport and Recreation (Cmnd 6200) recognised that the physically handicapped must be given the opportunity to participate in recreational activities not only by using facilities specifically designed for them, but also by sharing as many facilities and activities as is practicable with their families and the community at large. The Sports Council is empowered to make grants for the adaptation of existing buildings for sport and recreational purposes including appropriate provision for the disabled. The Council also produced advisory documents aimed at bringing home to all those who provide sports facilities the necessity of taking account of the needs of the disabled. Some of the nature trails established by the Nature Conservancy Council and voluntary conservation bodies are suitable for wheelchair users and for the blind. The Government sponsored "Quality of Life" experiments in the development of leisure activities carried out in 4 areas of Great Britain included in their programmes projects designed to increase or enhance the leisure activities of the 'disadvantaged', for example, the elderly and the physically handicapped. A report on the experiments, entitled "Leisure and the Quality of Life", was published in 1977 and has been discussed at Conferences up and down the country organised by the Regional Councils for Sport and Recreation. The Regional Councils include amongst their members representatives of local authorities as well as local sporting and recreational bodies. They advise statutory bodies on the allocation of grants for sport and recreation and are currently devising regional recreation strategies which will take into account the lessons learnt from the experiments.

~~August 1978~~ ALFRED MORRIS

18 SEP 1978

Address by State Secretary Anke Fuchs[*] at the Second European Conference of Rehabilitation International and Naidex 78

Measures to integrate the Disabled in the Federal Republic of Germany into working life, occupation and society

Ladies and Gentlemen,

It is a very positive development that in recent years the situation of the disabled has in many countries become a central issue of public concern. The discussion mainly focused on the disabled person himself. The personal environment of the disabled, mostly his family, which is also affected by the disability was, however, not given sufficient attention.

Therefore, our thanks and appreciation are due to the Royal Association for Disability and Rehabilitation and its chairman, His Grace the Duke of Buccleuch, V.R.D. for having made "disability in the family" the theme of this Conference, thus creating a public forum for the cause of the disabled and their families. This forum will be an illustration of the progress achieved in the field of rehabilitation in Europe and an opportunity for a scientific discussion of the manifold problems of rehabilitation and their practical solution.

The integration of the disabled into working life and society is a prime concern of social policy in the Federal Republic of Germany. The Federal government therefore welcomes the opportunity for an exchange of views and experience on the problems of the disabled and their families. We hope that it will provide us with new inspiration on how to improve the situation of families with disabled people among their members. A family may at any time be faced with the problem of disability as a result of an accident at work, a road accident, an accident at home or during leisure-time. Similar problems arise if one of the family members is affected by a chronic illness or if a child is born with a congenital disability.

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[*] Mrs. Anke Fuchs, State Secretary in the Ministry of Labour and Social affairs, Federal Republic of Germany, Bonn

Personal development and social integration in general are decisively influenced by the family, even more so in the case of the disabled, where the attitude of the family and its contribution to rehabilitation are of fundamental importance. Where a family is living in community with a disabled it is first and foremost the family which is responsible for his rehabilitation. To a lesser extent this is also true for a family who remains in close contact with a disabled family member in a nursing home or hospital.

A family with a disabled is under particularly great strain, which in its turn creates quite specific needs. Disability presents the family with particular problems such as an increased financial burden due to extra-expenditure for the adaptation of the home to the needs of the disabled family member, increased costs for attendance and care, restricted participation in outside activities, limited mobility and problems of training and employment. Under these circumstances the family has to make an enormous sacrifice. This is even more true where the breadwinner of a family is disabled. He himself is faced with a twofold problem because he is responsible for his family and has to live with his disability in the family without, however, being able to earn a living for himself and his family. The other family members have to make financial sacrifices and are often under great emotional strain.

These difficulties are quite frequently aggravated by the feeling that the disability is a prejudice to the social prestige not only of the disabled but of the family as a whole.

Brothers and sisters of a disabled suffer from this situation particularly during childhood since children lack the necessary self-assurance to dissociate themselves from the negative attitude of their environment. Moreover, they often have to put up with material sacrifices for the benefit of their disabled brother or sister and frequently they are under the impression to be deprived of the parental affection. This may cause jealousies leading to a dislike of the disabled. Their parents will most likely reproach them with their negative attitude and this in its turn gives rise to a guilt complex.

This situation may result in emotional imbalances frequently causing developmental disturbances.

Summing up, it may be said that the disability of one family member has considerable secondary consequences for the entire family structure. Both, the disabled and his family have to make an enormous sacrifice and have to adapt their behaviour to the new situation.

Therefore, it is the aim of German rehabilitation policy to alleviate the numerous problems of the families concerned. In our opinion this requires rehabilitation measures enabling the disabled to be largely independent from outside help. Rehabilitation and assistance for the disabled are of equal importance for his family.

Ladies and Gentlemen, I should now like to give you a survey of the measures implemented in the Federal Republic of Germany and designed to integrate disabled persons into working life, occupation and society. Rehabilitation must be an integral part of a modern social security system not merely compensating for an injury and its consequences, but enabling the individual to fully develop his own personality. In 1970 the government of the Federal Republic of Germany formulated an overall concept for the integration of the disabled and launched an Action Programme to promote rehabilitation. The programme is based on the principle that all disabled persons irrespective of their age and the cause and nature of their disablement should receive all necessary medical, occupational and social aids.

With the gradual implementation of this programme the situation of the disabled in the Federal Republic has been substantially improved.

Rehabilitation is an integral process with overlapping individual phases. Due to the limited time available I shall abstain from giving you an outline of the entire rehabilitation system in the Federal Republic of Germany, but shall rather confine myself to two essential areas of rehabilitation, that is occupational and social rehabilitation. These play an outstanding role in our efforts to alleviate or largely solve the problems of families with a disabled among their members.

Occupational rehabilitation is of fundamental importance for two reasons:

- work and occupation not only provide the source of income,
- but they have a decisive influence on the personality and self-assurance of the disabled and on the relationship with his family and his environment as a whole.

A disabled person needs qualified vocational training in order to be able to compete with able-bodied workers in working life. In the Federal Republic of Germany the disabled are trained in modern occupations with good employment prospects. In many cases training takes place in companies with suitable facilities. In other cases, where the disabled need medical, psychological, educational and social care, training is carried out in special rehabilitation centres. Past experience has shown that 20 % of the physically disabled and the disabled with hearing and speech defects as well as the mentally retarded and 100 % of the blind need to be trained in such centres. In these training centres a team of experts ensures that the rehabilitation process, based on an overall rehabilitation schedule taking account of the individual needs of the disabled concerned, prepares him for a new occupational activity.

In the Federal Republic of Germany there are two types of occupational rehabilitation centres:

1. Training centres for young disabled persons. In a first stage we plan to establish 24 centres of this type with some 7.000 training places; in a second stage an additional ten centres with 3.000 training places are to be built. 6.000 of all future training places are to be made available for the mentally retarded. 15 centres are currently in operation, 10 are under construction and 9 are in the process of planning.

2. Training centres for adult disabled persons, who, due to their disability, had to give up their former occupation and have to be retrained. It is planned to set up 21 centres of this type for adult disabled persons, 5 of which will be special centres for paraplegics and blind persons.

A total of 12.000 training places will be available in these centres. 18 centres are already operational, and 3 of them are currently under construction.

These training centres largely meet the demand which exists in this respect in the Federal Republic of Germany.

For the disabled participation in a training programme is free of cost. In order to avoid that the disabled and his family incur any extra-costs, young disabled persons receive a training grant. Adult disabled persons are granted a maintenance allowance amounting to 80 % of their previous wages so that they are able to maintain their former standard of living. In the course of training the disabled are covered by sickness insurance, accident insurance, unemployment insurance and pension insurance.

Ladies and Gentlemen, a highly qualified vocational training is certainly an important prerequisite for placing the disabled in a suitable job but experience in the Federal Republic has shown that this alone is not sufficient. Further aids must be given. Therefore, disabled persons may receive the following assistance:

- financial subsidies towards removal expenses and higher cost of housing, in cases where the new job made it necessary for the disabled to move;

- financial subsidies towards the travel expenses for the journey between the disabled person's home and his workplace,
- subsidies towards the purchase of a motor-car adapted to the needs of the disabled. Account is taken of the size of the family who may use it in their spare-time.

Assistance may also be granted to employers recruiting a disabled person. Where an employer has engaged a disabled, he may, for up to two years, receive 80 % of the wages paid to the disabled and may, moreover, be given a subsidy for the adaptation of the work place to the needs of disabled.

In the Federal Republic the Severely Disabled Persons Act is the statutory basis for the integration of the disabled into working life. This Act is applicable to all physically, mentally and psychologically disabled irrespective of the nature and cause of their disability provided that their earning capacity is reduced by at least 50 %. Disabled persons whose earning capacity is reduced by at least 30 % may receive equal treatment if their disability would prevent them from finding or keeping a suitable job.

Following, I should like to set out the three major principles of the Severely Disabled Persons Act. The Act stipulates:

- that any employer is under the obligation to fill a certain percentage of his posts with severely disabled persons. In case of non-compliance he is obliged to pay a compensatory levy,
- that severely disabled persons have a special protection against dismissal,
- that employment promotion measures are to be financed from the funds raised by way of compensatory levy.

All employers - including the public services - have to fill 6 % of their posts with severely disabled persons. Where this obligation is not complied with, the employer has to pay a compensatory levy of 100 DM per month for each post which remained unfilled.

The obligation to employ severely disabled persons and the compensatory levy proved to be successful incentives. On 1st October 1975 - that is one year after the entry into force of the legislation - about 650.000 of the posts were occupied by severely disabled persons. One year later the figure amounted to 710.000, and by the end of 1977 the number of posts filled with severely disabled persons had increased to almost 750.000.

Job security is to be achieved by a special protection against dismissal for the severely disabled. This protection is even more extensive than the general protection against dismissal for other workers: Notice of dismissal may be given only if the central assistance offices give their consent after a careful examination the circumstances of the case and the interests of both parties involved.

The funds raised by way of compensatory levy payable by employers who fail to comply with their obligation to employ severely disabled persons are used for employment promotion purposes. Subsidies are made available for:

1. the creation of jobs and training places adapted to the needs of severely disabled persons and for the recruitment of severely disabled persons on the basis of special programmes to bring down unemployment.

   In 1977 a first special programme with a volume of 100 million DM was implemented and as a consequence 8.600 severely disabled persons out of work could be placed into employment or training. A second special programme of the same volume is currently under way.

   Moreover assistance is granted

2. for the adaptation of workplaces to the needs of the disabled and for the provision of suitable accommodation, as well as

3. for the establishment and equipment of the training centres for disabled I mentioned earlier and for the creation and extension of workshops for the disabled.

   Sheltered workshops employ those disabled who, because of the nature and severity of their disablement, cannot or not yet work under normal conditions. In the Federal Republic of Germany there are at present 250 workshops admitting some 35.000 disabled. Disabled persons who are temporarily or permanently unable to find a job on the labour market are given the possibility to develop or regain their working capacity. We have planned to extend workshop facilities to a total of 60.000 places, in order to fully meet the demand in this field.

Ladies and Gentlemen, I do not want to elaborate any further on occupational rehabilitation in the Federal Republic of Germany. We do not claim to have solved all the problems in this field but we think that a decisive step forward has been made.

Occupational reintegration of the disabled is of crucial importance because it enables the person concerned to earn his own living thus being a basic prerequisite for social rehabilitation.

Ladies and Gentlemen, this leads me up to my next point, namely social rehabilitation which is the second key element in any rehabilitation process. In our opinion it plays an important part when it comes to alleviating the problems of the disabled and their families.

Despite their handicap disabled persons should have all opportunities of participating in community life like the able-bodied. Occupational rehabilitation can have positive results only if we succeed in achieving the social integration of the disabled; the disabled themselves wish to be fully integrated into society. It is indispensable for the development of their personality that they are able to have their own personal sphere of interest and to participate in their social environment. The living conditions of the disabled and their status in society must be improved by specific aids. These include in particular:

- the improvement of the mutual understanding between disabled and able-bodied,
- recreation facilities,
- sports for the disabled which, of course, have moreover also a therapeutic effect,
- the elimination of architectural and technical obstacles,
- housing adapted to the needs of the disabled,
- certain privileges compensating for disadvantages arising out of the handicap.

Ladies and Gentlemen, the able-bodied often react to disabled people with helplessness, pity or even aversion. The majority of the able-bodied approve of a social commitment for the disabled, but only few of them enter into direct contacts with them. Many disabled believe that their helplessness and dependence leave them with little choice but resignation. A change in the attitude of the disabled and the able-bodied and their mutual understanding can only be achieved by a better information of the public. In its public relation work the Federal government has taken account of this need in launching an information campaign on the nature and causes of disablements, the necessity of rehabilitation and the possibilities for the disabled to be integrated into society.

We support the organisations of the disabled in their efforts to gradually eliminate prejudice and to bring about a better comprehension of their problems.

Information must also aim at the disabled and their families since they have to master their situation.

Meaningful leisure time activities may help the disabled to accept their disablement and to take an active part in their further rehabilitation. Financial assistance is therefore granted to recreation and leisure time activities such as

- recreation facilities designed to preserve or to restore health and working capacity,
- general leisure time activities for the disabled and their families enabling them to communicate with other disabled and able-bodied people and to participate in cultural events, sports and other activities.

Priority is given to measures offering an opportunity for the disabled and the able-bodied to communicate during their leisure-time, because we believe that day-to-day contacts between the disabled and the able-bodied are an indispensable prerequisite for a better mutual understanding and more open-minded attitudes. Knowing about the problems of the other is the first step towards understanding them.

Sport activities for the disabled contribute to their rehabilitation for various reasons: they help to preserve or regain health and working capacity;

- they are of great psychological value since the exercise of the body and participation in sporting competition gives a new strength to live and greater self-assurance;
- they contribute to a more balanced exercise of bodily functions often neglected in normal day-to-day activities;
- and finally they encourage the establishment of personal contacts thus facilitating social integration.

Because of its medical importance, sports for the disabled are a statutory rehabilitation benefit in our country.

Disabled people are often faced with architectural and technical obstacles which make their social integration even more difficult. Such obstacles may hinder the disabled in using public transport, public roads and other facilities and make it a problem for him to participate in public, private and cultural events.

Since 1969 the government of the Federal Republic of Germany in cooperation with the Länder and the local authorities has stepped up its efforts to eliminate all obstacles which make life in the community difficult for the disabled citizens. Standards for the construction of public buildings and facilities have been developed. It has been laid down in specific construction regulations that public institutions such as meeting places, administrative buildings, public transport, plants and workplaces, schools, sport grounds and welfare facilities have to be easily accessible for the disabled.

Ladies and Gentlemen, housing is another element of social integration where the disabled has more pronounced needs than the able-bodied since due to their limited mobility their activity and experience logically centres around their home. Standards have been developed for the construction of housing for the disabled and financial subsidies are granted only where these standards are met. Construction regulations contain detailed provisions in this respect. Many new urban housing areas take account of the needs of the disabled.

Financial subsidies are granted to families with physically disabled family members because the adaptation of their home to the needs of the disabled automatically involves extra-costs. But of course the elimination of architectural obstacles and the creation of a more humane environment for the disabled can only be a gradual process and also in our country a lot remains to be done.

Another way of improving the situation of the disabled and their families is to grant them various kinds of privileges. Some of the financial privileges I mentioned earlier in connection with occupational rehabilitation. Special provision for the disabled is made in many other respects. This includes:

- tax rebates,
- free short-distance transport for certain categories of disabled,
- reduced telephone charges,
- exemption from postage for mail for the blind,
- rent allowances,
- exemption from radio and television licence fees for many disabled,
- financial subsidies for sports, cultural and other events.

The package of measures to revive the economy, which was agreed upon by the Federal Government in fulfilment of the pledges given at the world economic summit in Bonn, includes the lowering of the retirement age for the severely disabled.

This is another important milestone in the rehabilitation policy pursued by the Federal Government since 1969.

From January 1979 severely disabled persons will be able to retire at the age of 61 and, starting from 1980, at the age of 60.

[- instead of 62 as it is/now -

In the preparation of this bill the Federal Government was guided by humanitarian and labour market policy considerations. On the one hand older insured persons with a considerably reduced working capacity and resulting difficulties in exercising a regular employment are to have the option of withdrawing from working life at an earlier age. Thus the Federal Government offers some 70.000 severely disabled persons the possibility of early retirement.

On the other hand the Federal Government expects that this measure will have a positive impact on the employment situation. It presumes that the resulting vacancies will primarily be filled with younger severely disabled persons who are at present out of work.

Contrary to some other countries the Federal Government continues to believe that the growing exertions required in working life call for flexible structures to ease the stress on the individual worker. This is even more true for a disabled worker who is exposed to additional physical and emotional strain.

Ladies and Gentlemen, occupational and social rehabilitation are certainly the two key elements for an improvement of the situation of families with a disabled among their members. What is even more important is to prevent or control disablements. This is the only way to avoid or at least limit the problem of disability in the family.

Therefore we are seeking to develop adequate organisational structures for early diagnosis and treatment of disabilities in the Federal Republic of Germany.

At present there are several socio-pediatric centres in the Federal Republic of Germany which offer treatment for children with disablements and developmental disorders of all kinds. Priority is given to out-patient care which is based on a comprehensive treatment schedule and includes instruction of the parents so that they can continue the therapeutic measures, therapy recommendations to doctors, therapeutic experts, kindergardens and schools, progress control and follow-up examinations. Children with serious behaviour and adaptive disorders resulting from their disablement receive integrated in-patient treatment covering aspects of general medicine, behavioural therapy and medical pedagogy. During this treatment the mother or father stays together with the child in the early diagnosis centre. They are to learn how to take an active and efficient part in the treatment process, because the parents play an essential role in furthering the optimum development of the working capacity, the receptivity and the ability of the disabled child to adapt to its environment and to make contacts.

Under the circumstances already outlined the integration of the disabled into working life, occupation and society will greatly contribute to alleviating or solving the problems of the disabled and their families. A rehabilitation policy aimed at offering adequate employment to all disabled people and thus facilitating their social integration, creates favourable conditions for able-bodied and disabled family members living together in harmony.

The problem of the disabled is a challenge to us which we accepted and made a prime concern of our social policy. We pursued this policy also in times of economic difficulties. The substantial progress achieved over the past few years will, however, not make us forget how much still remains to be done to ensure that this category of persons remains the centre of our attention. In my opinion the quality of a country's social policy can be judged by what this country does for the weakest members of its society, namely for its disabled citizens.

In its concern for the disabled the Federal government acts in concert with the numerous governmental and private organisations in our country which in an altruistic manner successfully strive for better opportunities for the disabled.

Quality of life must not be a privilege of the able-bodied.

THE BELGIAN SOCIAL REHABILITATION SCHEME FOR THE HANDICAPPED.

A. MARON, Director General-Director of Administration of the National Fund [x]

The Belgian Social Rehabilitation Scheme for the Handicapped was set up by the laws of 28 April 1958 and 16 April 1963.

The national institution bearing the title "The National Fund for the Social Rehabilitation of the Handicapped" was created for the purposes of ensuring the implementation of the provisions of the law, two of which are given below :

1) The National Fund for the Social Rehabilitation of the Handicapped offers its services to any handicapped person, either Belgian or alien, wishing to ensure his or her readaptation and rehabilitation.

   To this end, the National Fund, in collaboration with medical and other experts, draws up individual programmes for the rehabilitation of each handicap, ensures its proper implementation and bears the costs for readaptation and rehabilitation, when these costs are not borne by bodies such as Social Security etc.

2) The National Fund is responsible for the promotion of rehabilitation in the following domains :

   a) Medical rehabilitation centres
   b) Specialised vocational guidance centres
   c) Vocational training centres
   d) Sheltered workshops

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[x] for the Social Rehabilitation of the Handicapped. Belgium.

THE BELGIAN SOCIAL REHABILITATION SCHEME FOR THE HANDICAPPED

A. MARON, Director General-Director of Administration of the National Fund[x]

The subject of this conference being the handicapped and their families, I think it would be fitting to give you an outline of the Belgian Social Rehabilitation Scheme for the Handicapped.

This scheme, in practice, has several aims, of which the most important, in the context of this conference, is that of providing for the handicapped and their families a national and official body responsible for giving them assistance in all problems they come up against during the period of rehabilitation.

A national institution known as "The National Fund for the Social Rehabilitation of the Handicapped" was set up in 1958 for giving assistance to handicapped in the following ways :
- for research on better rehabilitation programmes and
- bearing the costs for these programmes

Furthermore, the National Fund is responsible for the development of the necessary methods of rehabilitation whose scope we shall examine.

It should be said first of all that the National Fund gives no money in pensions or compensation to the handicapped, since this sector has, for many years, come under different laws governing compensation and reparation payments. Also, because the Fund is responsible for rehabilitation promotion, it has to take account of schemes and institutions set up under the ministerial departments involved such as the Ministry of National Education and the Ministry of Public Health and Family Welfare.

With regard to the welfare of the handicapped, the Belgian social rehabilitation scheme makes two distinctions which seem to me to be of fundamental importance :

1) It is designed only for handicapped people who, after a shorter or longer period of rehabilitation, are likely to play a part in the economic life of the community, even if under special provisions catering for disability.
2) It is not open to the socially handicapped. However, when it is a question of a disability due to physical or mental causes, the socially handicapped may avail himself of the provisions for rehabilitation under the scheme.

The scheme covers two aspects :

1) At individual level, the Fund is responsible for drawing up and ensuring the proper implementation of rehabilitation programmes for any handicapped person wishing to avail himself of the scheme, and for bearing all the costs not covered by other schemes, such as Social Security which would otherwise have has to be borne by the applicant himself.

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[x] for the Social Rehabilitation of the Handicapped. Belgium.

Until now, there have been 300.000 programmes which have been worked out in this way, or which are in operation at the present time.

2) At collective level, the Fund is responsible for setting policy objectives as well as the relevant standards and for ensuring the efficient coordination of institutions whose task it is to carry out this policy on a practical level. These institutions include the following :

1) Centres or services for medical rehabilitation
2) Centres for specialised vocational guidance;
3) Vocational training centres;
4) Sheltered workshops

DESCRIPTION OF THE SCHEME

A. SCOPE

The scheme applies to persons, either Belgian or alien, who fulfil certain specific conditions and whose possibilities for work are limited due to physical disability of not less than 30 % or mental disability of not less than 20 %.

The law applies to all handicapped persons, whatever the nature or cause of their disability, and irrespective of their status.

B. APPLICATIONS

The aim of the legislation is to ensure that all handicapped persons are informed of the benefits available under this scheme.

The application is made by the handicapped person himself or by his legal representative and admission is granted provided that the handicapped person fulfils the entrance requirements.

C. MEDICAL REHABILITATION AND PROVISION OF EQUIPMENT

The legislation emphasised the value of **medical** rehabilitation in the law op 16 April 1963.

C_1. INDIVIDUAL REHABILITATION

The idea of practical or physical rehabilitation is the natural continuation of actual medical treatment, since it ensures that handicapped persons not only receive the best medical care but also helps them to use their remaining ability and provides guidance with regard to this ability so that adaptation to the most appropriate work is possible.

Medical rehabilitation therefore involves both considerations of a strictly and specifically medical nature and all aspects which might contribute to finding suitable work.

In this respect, the National Fund is geared towards advising the handicapped person on the medical or surgical treatment which will give him the greatest degree of rehabilitation thereby giving him or improving ability to work.

Furthermore, the Fund will bear all or part of the costs for the treatment which the handicapped person has been advised to undergo insofar as these costs are justified, possibly taking account of legal or statutory subsidies as well as subsidies for the handicapped persons concerned or for their families.

C_2 CENTRES FOR MEDICAL REHABILITATION

The Management Council of the National Fund for the Social Rehabilitation of the Handicapped has drawn up the regulations for the approval of the "Centres or services for medical rehabilitation" on the basis of the following two considerations :

On the one hand, the idea of physical rehabilitation in itself and, on the other, the structures of the centres and the conditions which they should abide by so as to ensure their efficiency.

In this context, the following centres have been set up or approved :

a. Centres for handicapped persons with motor or similar disorders

b. Centres for handicapped persons with cerebral motor or neurological disorders

c. Centres for cardiac patients

d. Centres for handicapped persons with hearing or speech disorders

e. Centres for the mentally handicapped

f. Centres for persons with sight disorders

Formulation of specific regulations pertaining to approval of medical rehabilitation centres, firstly, helped to draw the attention of more and more specialists and technicians to the field of rehabilitation and, secondly, helped to promote classification of these institutions.

We should in fact point out here that the National Fund for the Social Rehabilitation of the Handicapped takes on 60 % of the costs for building, adapting and equipping practical rehabilitation centres and also subsidies the operating costs of such institutions.

In 1964, approval was given to 18 practical rehabilitation centres and on 31.12.1977 there were 222 such centres.

These centres come under the following classifications :

					Per 10.000 inhabitants
a) Motor disorders	: 53	with	7.181	rehab.places	7,3
b) Cereb.Motor disorders	: 6	"	257	" "	0,2
c) Cardiac disorders	: 16	"	598	" "	0,6
d) Hearing/speech disord.	: 33	"	1.890	" "	1,9
e) Mentally handicapped	:113	"	8.128	" "	8,3
f) Sight disorders	: 1	"	19	" "	0,02
	222		18.073		

C$_3$ SPECIALIST DOCTORS IN REHABILITATION

One of the Government's main concerns was to lay particular emphasis on the specialist doctor in rehabilitation since his work is so vital to rehabilitation centres.

Officially known as "Specialist doctors in Rehabilitation" these doctors are approved by a committee set up within the Ministry for Public Health.

C$_4$ PARAMEDICAL REHABILITATION STAFF

The Belgian Rehabilitation Scheme has put particular emphasis on the approval of qualified paramedical staff, such as nursing, kinesiotherapeutic, orthopaedic, dressing, acoustic, ophthalmic, ergotherapeutic, logopaedic and orthoptic staff.

D. ACADEMIC AND VOCATIONAL GUIDANCE

Belgium has a network of vocational guidance centres and medical and psycho-social centres.

These centres are open to all handicapped persons and applicants who fulfil the requirements and provides them with proper guidance.

Nevertheless, it is obvious that due to the large number of tasks which have fallen to them, these centres cannot offer specific specialisation in all the problems arising from handicapped persons' needs and they are faced with real difficulties when having to advise some handicapped people whose disability is of such a nature or so serious that the applicants cannot be fully rehabilitated.

This is why the legislation has made provisions for the promotion of specialised vocational guidance for handicapped persons.

The 1963 legislation therefore provides aid from the National Fund for two types of institution :

a) So-called ordinary institutions, i.e. an academic or vocational guidance office or a medical and psyco-social centre;
b) So-called specialised institutions, i.e. the vocational guidance centres or services set up under the law.

D$_1$ SPECIALISED VOCATIONAL GUIDANCE CENTRES

The specialised vocational guidance centres are distinct from other centres by virtue of :

a) qualifications of the staff;
b) equipment used;
c) premises used.

The National Fund has therefore introduced specific conditions for approval on the one hand and a method of granting subsidies on the other.

The combination of these two factors has also made its contribution to establishing the idea of rehabilitation in Belgium since the number of specialised vocational guidance centres went up from 24 in 1964 to 70 on 31.12.1977.

D_2 VOCATIONAL GUIDANCE COUNSELLORS OR PSYCHOLOGIST APPROVED FOR THE TREATMENT OF HANDICAPPED PERSONS.

Due to the desire to acknowledge the particular qualifications of certain vocational guidance counsellors or psychologists, the statutory regulations, included in the National Rehabilitation Scheme, makes provisions for the approval of counsellors or psychologists specially qualified in rehabilitation.

Under this section of the provisions Belgium now has 91 persons who have been approved to work in this field.

E. ACADEMIC EDUCATION

With regard to academic education, the Ministry for National Education has under its responsability a network of nursery, primary, junior and senior schools as well as their curricula. These establishments are designed for the education of both normal and handicapped children.

A law passed on 6 July 1970 also determines the status of special education for handicapped persons.

F. VOCATIONAL TRAINING AND REHABILITATION

Vocational training for handicapped persons is generally assured by the special educational establishments which have been provided to extend school education.

The educational establishments, set up to meet the needs of persons with specific disabilities, cannot however give the handicapped person access to the approximately 2000 professions which exist in the industrialised countries and are therefore restricted to providing training in certain careers.

For this reason, the National Fund covers the following areas :

1) A full school education, with a view to placement, geared, in specific cases, to vocational training, rehabilitation or re-education;

2) A traineeship in industry, the professions and business world, the merchant navy and sea fishing;

3) A special traineeship for vocational rehabilitation for handicapped persons;

4) A traineeship or vocational rehabilitation programme at an advances vocational training centre for adults, set up or approved by the National Employment Office;

5) A traineeship or vocational rehabilitation programme at a vocational training or rehabilitation centre for handicapped persons.

In this context, I shall only mention in some detail, the three types of centre most often run by the National Fund.
These are :

1) The vocational training centre for handicapped persons

This is a system of vocational training centres for handicapped persons which is well known in various countries.

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These centres of which there are in Belgium (9), provide vocational training for some 350 handicapped persons.

2) The most widely used system for vocational training of handicapped persons is undeniably the special traineeship for handicapped persons.

This traineeship agreed on between an employer and a handicapped person and endorsed by the National Fund, has, in our opinion, many advantages. Some of these are :

a) An objective can be set which is adjusted to the intellectual and physical ability of the handicapped person;

b) The traineeship is organised over a period which is also determined in accordance with the person's abilities;

c) It is possible to find a "place of training" which is generally near to the handicapped person's home;

d) It offers a greater range of jobs;

e) The specific terms of the traineeship mean that the handicapped person is in a working environment;

f) By the end of the traineeship, the handicapped person has made a place for himself, both morally and physically, within the firm and in most cases, the employer keeps the handicapped person on as an employee.

3) Integration into higher education : this system is used for handicapped persons who possess the requisite level of intelligence to follow courses in higher education (university or para-university) whose financial means, however, would have otherwise excluded them from such possibilities.

In such cases, the National Fund takes over the costs for such studies, travelling expenses and compensation payment, in lieu of a salary, throughout the duration of studies.

This system has meant that many handicapped persons have had access to professions from which their family background would otherwise have precluded them.

We would point out that in all cases where the handicapped person is undergoing vocational training, the following are provided by the National Fund :

1) Compensation in lieu of a wage, the amount of which is calculated on the basis of the minimum wage recognised in the job being trained for;

2) Reimbursement of travelling expenses and possibly accomodation expenses

3) Reimbursement of the costs for training equipment.

G. PLACEMENT

All the rehabilitation provisions would have a very limited scope were they not gratified by the satisfaction gained from the end results for which all these effort have been called for and sometimes necessitated for the handicapped person.

This is why Belgian legislation has made provisions for :

a) Obligatory employment of handicapped persons in private enterprises, particularly in industrial, commercial and agricultural firms;

b) Obligatory employment in public administration and public concerns;

c) In trades and in self-employment;

d) In workshops.

OBLIGATORY EMPLOYMENT OF HANDICAPPED PERSONS

The said law actually includes an obligation on the part of private entreprises, public administration and public concerns to employ handicapped persons.

However, except in the case of public administration, these measures have still not been applied.

In this respect, we would like to point out several incentives relating to the placement of handicapped persons.

1) Within the framework of the law on economic expansion, the State, when granting aid for the setting up or extension of a company, makes the obligation on the part of the company to employ a certain number of handicapped persons amongst its new workers compulsory.

2) Under the collective labour agreement concluded on 15 October 1975 within the National Labour Council, the employer is authorised to pay the handicapped worker a wage which is proportional to his output; the difference between the "real wage" and the normal wage is made up by a subsidy from the National Employment Office or the National Fund for the Social Rehabilitation of the Handicapped.

3) Subsidy for remuneration and social contributions paid for a maximum of one year to the handicapped person who has been given work or who has a new job; this is a flat rate subsidy designed to cover the employer's loss in profit arising from adaptation of the handicapped person to the work.

4) Taking on of the costs of adaptation to the job; the National Fund takes on the costs of adjustment or access to the job.

5) Subsidies from the National Fund towards the cost of clothing and working equipment where these costs are not borne by the company.

6) Subsidies for the additional costs incurred by transportation of the handicapped person to his place of work.

The results obtained at the end of the individual rehabilitation programme in which the handicapped person has participated together with all the personal factors to be taken into consideration such as the person's family and social situation and his choice of job, make it possible to find him the most suitable job.

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X X

Legislation on the National Fund makes provisions for four sectors for placement of handicapped persons.

These are :

- Private enterprises

The National Employment Office which assures placement of candidates for work in the private sector is able to meet the requirements of the handicapped person in this respect. To this end, the services of the National Fund notify the specialised placement officials in this body's regional offices of the information needed to help find work for handicapped persons.

- Public administration and public concerns

A royal decree of 1 December 1964 made provision for specific regulations relating to the admission of handicapped persons to so-called "public" jobs. These provisions take the place of the strict aptitude regulations demanded of candidates for these jobs, by introducing more individual criteria for the medical examination which is carried out in order to détermine the candidate's ability to do the job.

Furthermore, a measure has been taken in order to encourage the employment of handicapped persons in State administration. It was laid down by the royal decree of 11 August 1972 which reserves 1.200 jobs for handicapped persons registered with the National Fund in the State administration and 90 jobs in para-state establishments.

The National Fund for the Social Rehabilitation of the Handicapped helps to implement this measure in collaboration with the "Permanent Secretariat for Recruitment of Staff for the State".

- Trades and Self-Employment

The setting up of handicapped persons in trades and self-employment is also encouraged by the royal decree which stipulates that the National Fund shall be responsible for granting or guaranteeing loans with or without interest, in money or in kind.

- Sheltered Workshops

In this respect, the legislation has also made provisions for placement in sheltered workshops of handicapped persons whose disability, by its nature or degree, prevents placement in an ordinary firm.

H. PLACEMENT IN SHELTERED EMPLOYMENT

In certain cases, the degree of disability is such that the handicapped persons are not able either temporarily or permanently to carry out an occupational activity under normal working conditions.

This is why workshops have been set up for these people. These workshops, known as"sheltered workshops" provided the specific conditions which will enable these people to carry out an occupational activity.

The subsidies granted by the National Fund for the Social Rehabilitation of the Handicapped come under three categories :

- subsidies for running costs;
- subsidies for setting up, extensions and adjustments;
- subsidies for remuneration and social contributions, subsidies remuneration of skeleton and the coats for medical provisions.

Implementation of this policy to promote the sheltered workshop has not been long in showing results and the increase in the number of sheltered workshops set up under this policy is quite considerable.

Starting with 18 sheltered workshops in 1958 employing 751 workers, the number of workshops went up to 142 in 1978 employing 10.500 workers.

I. SOCIAL AID

It often happens that social rehabilitation of the handicapped is slowed down by various obstacles of a material nature.

Therefore, it has been necessary for some handicapped persons :

- to have their cars adjusted depending on their disability so that they themselves can drive;
- to have adjustments made to their homes so that they can move aroung without difficulty and use all the modern conveniences;
- to have special equipment, the use of which is indispensable because of their handicap; for example, many blind people need a tape-recorder or an optacon and deaf people need a lighting device attached to their doorbells, etc.

In such cases, the National Fund for the Social Rehabilitation of the Handicapped, grants handicapped persons financial subsidies in social aid. These subsidies are designed to help them cover the coasts which they must pay for equipment to compensate their handicap on the material level.

Together with these material aspects, it is important to mention other activities which the Belgian Scheme undertakes to ensur as complete an integration as possible of the handicapped person in society:

1) Parking discs for parking for unlimited periods are issued to handicapped persons who have a permanent disability of at least 50 % affecting the lower limbs or a permanent disability of not less than 60 %;
2) Free travel passes for the trams are issued to blind people or those with seriously impaired sight;
3) Concession or free travel passes are issued to this same category of persons for the Belgian railways;
4) Participation in numerous studies such as studies on adjustments which can be made to railway carriages and railway stations etc.

Contribution to the European Conference of Rehabilitation International on the theme "Disability in the Family" at Brighton on Monday, 18 September 1978 at 4.45 p.m. by Mr. M.W.J. Menken, L.L.M., the Netherlands.

Mr. Chairmen, Ladies and Gentlemen,

When I was asked some time ago to talk to you on the theme of "Disability in the Family" I must confess that I only accepted after much hesitation. As the programme states, I am expected to give you an introduction to this theme from the Dutch point of view in the space of just half an hour. I think you will agree that this is a virtually impossible task, and one which I can only accomplish by taking into account my limitations. In fact, "Realize your limitations" might and should be the motto of this conference, and I hope to be able to demonstrate, in the brief time available to me, the validity of this phrase both for the family and its handicapped member as well as for society as a whole.
I mentioned the ability to recognize one's limitations.
- If these problems are to be dealt with in a scientific manner, they must also be considered from more than one point of view, for example by sociologists, psychologists, etc. But we are limited here to just myself, and my reflections based on my personal experience and daily work as a policy officer of the Department for Social Provisions of the Dutch Ministry of Social Affairs.
- The second limitation concerns the type of handicap: namely those present at birth or acquired in early youth. I shall disregard the problems of the mentally and intellectually handicapped, and of the double-handicapped.

First of all, I want to make it clear that there is no such thing as the handicapped person in such a general sense. Though this may seem to be a play on words, I hope I can show you the truth of that statement.

The problem of the handicapped person in society is not essentially concerned with a group of persons clearly distinguishable from all others! People seem unwilling to realize this. Perhaps it is because we are all in a certain sense handicapped, we all have to contend ourselves with visible or invisible limitations. Every one is tied in a thousand and one ways: to being a housewife, to one's job, to the environment, and to one's physical and mental limits. These limits can

.../...

sometimes be very oppressive. When do we actually call a person handicapped? To explain that to you I should like to draw a distinction between two aspects, namely disability, which is an objective handicap, and "handicappedness", which is a subjective handicap. Disability is a physical or mental defect having an objective characteristic which is generally described by a medical practitioner. A handicap could be defined as the way in which that defect is subjectively and personally experienced. In a nutshell: disability is being disabled, and a handicap is the sense of being disabled. I hope to be able to show you why I feel it is necessary to make this distinction.

We can distinguish various kinds of objective handicaps, as you all know:

1. Mental handicaps, whereby one's intellectual powers are behind, or have a totally different form from, one's 'normal' powers.

2. Physical handicaps, whereby physical properties are below standard while one's intellectual powers are normal. Think of deformations, injuries caused by accidents and the results of illness.

3. Sensory handicaps, whereby hearing, speech and sight can be affected.

4. Mixed forms of the above.

Now we come to the term subjective handicap. This need not be in any definite relation to an objective, actual handicap, for not every physical limitation need be experienced as a handicap. The question of whether a person is handicapped can only be answered meaningfully with reference to the demands which a certain situation makes on that person. If an invalid is suitably equipped he does not need to experience his invalidity as a handi cap. Because of the special equipment and facilities of, for example, "Het Dorp" near Arnhem its inhabitants are able to lead lives that are as independent as possible, without being excessively disabled.

On the other hand, a person may easily feel handicapped or impeded without suffering any physical defect in the strict medical sense. For a girl, having a snub nose may be experienced as a real handicap - if she feels it detracts from her beauty - while nobody would call a snub nose a real defect, whereas another girl who has serious difficulties in walking will scarcely experience it as a handicap if she has a wheelchair.

Discrimination, both positive and negative, occurs everywhere. In order to maintain a firm grasp on our subject we must bear in mind that "the handicapped person" does not really exist, at least not with regard to the experiencing of a handicap. A spastic and a polio patient are both handicapped, but the worlds of the two are totally different and so is their experiencing of the handicap. The same applies amongst spastics themselves.

Nevertheless, I consider that there are a number of factors which - also from a more objective angle - to an invalid may form the handicap, the real impediment.

Without mentioning them all, I would think that the main handicap-forming circumstances are: the barriers which a physically handicapped person encounters in society. Besides the emotional, I am thinking especially of the architectural barriers: stairs, doors, etc.

Another handicap-forming factor of importance is the reactions from the people around us. A quick test of one's conscience reveals the following facts: shame, feeling uncomfortable, fear, lack of knowledge, etc. The most important factor, however, I think, is that in society the standards predominate which are those of the vast majority of the non-handicapped, standards to which the handicapped persons generally have to adapt themselves. The handicapped are perpetually confronted with the society of the non-handicapped. In general, this society regards as the most important values those of occupation, work success, prestige and status (married or unmarried). Those who fail to meet these values form a peripheral group and according to the general norm thus fall outside "normal" society. In other words, what is experienced as a handicap by the handicapped is co-dependent on the value attached by society to various facets of life. So far I have talked about the handicapped person as a person, but now I should like to touch briefly upon the handicap itself and its consequences for the family. The family, too, can find it difficult, though mostly not impossible, to come to terms with a handicap. One of the first barriers to be overcome is to establish one's own attitude towards having a handicapped member of the family. This attitude will be a determining factor for relations to "the world outside". The outside world mostly expresses its aversion to handicapped persons in an emotional way. The family, but the parents in particular, should never forget that all such expressions are those of uncertainty and fear. They may manifest themselves as mockery or sympathy, and as disgust or over-indulgence. The way a family reacts to its environment determines to a considerable degree the attitude which the outside world will adopt towards that family. The position of the family in the district, and the characters of the parents and other relatives is of prime importance. Standards of human dignity, religious views, taboos and scientific understanding act both individually and in combination to determine the way in which a handicapped person and his family are experienced and approached. I now relinquish this theme for further elaboration by sociologists, psychologists, and other "ologists". I hope this congress will have some fine contributions.

This brings me to the efforts of Dutch society on behalf of those of its members who are in some aspects perhaps less privileged. I say "in some aspects perhaps less privileged" but I feel that this group of persons could in fact be considered as more privileged, because they discover human values which may perhaps not be so readily found by others. They learn, for example, to experience values such as perseverance and tenacity, the fighting spirit, human fellowship and love in such a way that their lives can receive a completely new dimension.

In the Netherlands, too, one is realizing more and more that the social paradise - and especially social security and social insurance schemes - is at risk. One is even speaking of its end drawing near.

As a result of rising unemployment, inflation, collapse of the monetary system, higher raw material prices, economic recession, rising of the average age of the population, and an increasing number of disabled people (both physically and mentally handicapped persons), big social and economic problems have, within a short time, arisen. The resources entailed have consequently reached unprecedented proportions; in some countries the social security budget already exceeds the state budget.

The number of non-working persons is ever increasing, the number of working persons is ever falling; it has been calculated that, at the moment, one in five persons works productively, i.e. adds economic value to the national income. In other words: one Dutchman works for himself and four others!

These problems will especially have their effect on the weakest groups in our society : the disabled, the aged, widows and orphans, the unemployed and the minimum wage earners.

It means that especially the disabled are facing an extremely difficult period. The social security structure is in grave danger. Extension of the existing social security will no longer be possible and existing social security will be affected ....
Social paradise almost lost!

A separate, general and overall act for the handicapped and/or for rehabilitation - that is to say : an act that arranges the complete organization, planning, co-ordination, assessment, research and financing, as regards the medical, educational, vocational, social, housing and income aspects (grants, benefits, measures, provisions, assistance and rehabilitation activities in general) of rehabilitation - is unknown in the Netherlands.

Several Acts do exist, however, that can be regarded as specific acts for the handicapped and disabled, due to their specific purpose and actual extent. I may as well mention :

The General Working Incapacity Act,
The General Special Sickness Expenses Act,
The Special Educational Regulation (part of the Primary School Act),

and other statutory regulations, mostly for very specific groups and categories.

But those Acts are specific acts for specific purposes, not organically linked to each other, not brought in a frame-work, not designed from a universal, comprehensive or joint conception.

Nevertheless, since 1968 there is an Interministerial Steering Committee on Rehabilitation Policy, for the co-ordination of the Government policy concerning the handicapped and their rehabilitation; on this Committee are sitting representatives of Education, Health, Social Affairs, Defence, Social Welfare, Housing and Finance. Within this official body we are trying to co-ordinate, to set the priorities, to negotiate with the private national associations (National Council for Care of the Mentally Handicapped, Netherlands Association for Rehabilitation) and to prepare legislation.

In the field of rehabilitation in the Netherlands we have a sort of dualistic system: the government and local authorities have a co-ordinating, stimulating, advising and financing task, but the provisions for the handicapped are not the primary concern of government and local authorities. They are mainly the concern of private organizations, having a religious, ethical, ideological or non-denominational but private basis.

Nevertheless, there are municipal health authorities and social services which organize welfare services for the handicapped. The provision of suitable employment, including sheltered employment, is also to a great extent a public matter, although financed by the government.

Definitions and comparability

We are aware of the well-known 1955 - Vienna definition of Rehabilitation ("the complex of regulations and activities designed to raise the physical, mental, social, professional and economic faculties to the highest possible degree"), but this definition is not officially adopted in any legislation or regulation.

I believe, however, that this definition is no more up to date, incomplete and no longer a determining factor for our policy. Rehabilitation now is more society and integration oriented than it was before. Not only the individual is our object but society as a whole and the social milieus too- we try to undertake social action and we attempt to make our society accessible in a physical sense (buildings, houses, traffic and transport, mass-media). New methods are being introduced, new possibilities are being accentuated, new ways in the fields of recreational activities and sports, and new forms of collective residential housing. And: the disabled themselves have a growing sense of purpose and awareness of their own capabilities (emancipation drive).

The same gap we find with regard to a definition of the handicapped or the disabled (these terms are interchangeable in the Netherlands): there are only specific definitions in specific Acts for their specific purpose.

This multitude or even absence of standard definitions is - I admit - a big handicap for comparing our legislation and our overall situation and that of other countries.

Even in my country we have the situation that, e.g. home help for (a family with) a disabled person can be provided by a home help service; however, it is also possible, in some cases, that an amount in cash to pay for this help is put at the disposal of this family. In my opinion, this is due to the fact that, in most developed countries, we have not only made - for objectively good reasons - distinctions and even separations between the two types of insurance acts (for cash provisions and pensions and for provisions like medical treatment, social work, education and employment) but we have also failed to gear these two types of legislation properly to one another; the executive bodies of these acts are mostly different from each other. And between these two fields we find that no man's land of the personal provisions (means of transport, housekeeping adaptations and equipment, etc.) Oh, I know that many countries have incorporated, in their workers' Disability Insurance Scheme, provisions like the making available of a motor car and payments for adaptations in dwellings, but if the person concerned is not a worker, we have to find legal constructions for analogous implementation and escape-exceptions- in other countries such provisions - on behalf of A.D.L. - are part of the Health Insurance Fund Act. We have solutions, I agree, but not principal ones.

In my country too it is true what some people say: "the whole system of social insurance acts is going to be so intricate that even the experts cannot find their way in it; and the handicapped themselves, for which all these acts and laws are made, are confused and do not understand it at all".

A very important new Act is the:

General Working Incapacity Act (Dutch : A.A.W.).

The A.A.W. defines the insured person as follows:

"Unable to work is the person who, as a result of sickness or defects, is wholly or partially unable to earn the same wage as earned by similar persons who are physically and mentally sane, with the same training and background, performing similar work in a similar location, while such a person performs labour assigned to him within reason with regard to his strength and ability, his training and his former profession".

The A.A.W. (in force on the Ist October 1976) applies to all citizens up to the age of 65, i.e. employees, the self-employed, "early handicapped persons" (by congenital infirmities or persons who got handicapped later and could not work until their eighteenth year) and other persons, like retired tradesmen.

The A.A.W. knows two kinds of provisions, notably :
the indemnification benefits or wage-compensations and those provisions which are meant to preserve, recover or improve the ability for work and those which tend to improve living conditions.

The former provisions are extended in order to enable the handicapped person to earn or to earn more. For this purpose, e.g. motor cars may be furnished (on loan) in order to enable the handicapped person to go to work and machines may be adapted in order to achieve better production. The latter provisions are of the order of compensating, as well as possible, the handicaps encountered in daily life (means of transport in case of full working incapacity, installing a lift at home, sanitary provisions). Under social security the minimum benefits are approximately at the same level as the legal minimum wage.

A great variety of special expenses and extra expenses can be provided for under the National Working Incapacity Act (A.A.W.) and other acts. Besides that, I will mention the provisions of the health insurance scheme and those of the Ministry of Housing. Provisions may be in kind, cash, compensations (up to 100%), or tax facilities.

Examples are :

. drugs, special aids, appliances (wheelchairs, hearing aids);
. adaptations in and to the home : a subsidy regulation of the Ministry of Housing (subsidy for building and reconstruction, 100% subsidy for adaptations to an existing dwelling, like installing a lift, sanitary provisions).
. pysiotherapy;
. domestic help;
. extra help in the home;
. extra travelling expenses: by rail, bus and taxi for work, study and leisure purposes;
. motor car; car on loan for disabled persons and their family; (the same applies to other electric means of transport and those with petrol engines);
. adaptations to means of transport;
. specific courses for improving, maintaining the working capacity;
. adaptations to the working place (sanitary provisions, lift, doors, doorstep,

only for the disabled worker's environment, not to the whole building or factory as a general measure);

. extra wear and tear of clothing, including washing and footwear : (compensation of this cost is given because this cost arises from the wearing of artificial limbs and protheses);

. combination of home help and district nursing/nursing home help;

It is not possible to say in general, what factors determine whether the expenses are being paid by cash benefits or by the free or subsidised supply of goods or services.

Generally speaking we have the following sequence: first of all help may be given by the organizations of the functional or general welfare-services, services available for all citizens (health, social work, employment services, school services, housing), under the scheme of social insurance or subsidised.

Secondly, help may be given in kind or cash by social insurance schemes to provide a sufficient income and complementary provisions (for improving living conditions), and thirdly, the Public Assistance Act can provide financial support.

Finally, the tax system can be adjusted in such a way as to provide some relief when great extra costs are due to the handicap.

Mr. Chairman, Ladies and Gentlemen,
I hope that I have succeeded in demonstrating:

a. the relativity of being handicapped
b. the relativity of disability in the family
c. how Dutch society endeavours to provide the means to enable such families and the handicapped to integrate.

I trust you will forgive me if I seem to have made a number of propositions in a rather cryptic statement. In general, I can summarise them as follows:

- In view of the democratic principle that all men are born equal, in the sense that the dignity and importance of the individual transcend differences in ability, one should see these persons first and foremost as persons and not treat them as pathetic and under-privileged creatures. The word 'pathetic' should be dropped immediately.

- One should be fully aware of the nature of the disability and the consequent limitations, and made every effort to stimulate those faculties which are fully present.

- Disability is more of a (socio)psychological problem than a technical problem. One should therefore take full account of the person's psychological background.

- To be handicapped is an existential fact: an aspect ("problem") inherent to life, which will never be definitely solved. In this case, that aspect is having to live with a physical form which deviates from what is regarded as normal, with all the resultant implications.

- In the approach to the handicapped one will have to seek the balance between an excessively indifferent attitude (as if nothing was the matter) and an excessively solicitous attitude (because they miss so much in life).

It is precisely in the modern world where everything and everybody seems to be in a rush, where nobody seems to have any time for anybody else and where we seem doomed to become the victims of self over estimation in many ways. The handicapped person, I feel, has an extremely important role to play as he forces others to realize the limitations of their existence.

If we assume that for the development of the handicapped person's personality it is best that he should realize what he is able to do and that he should direct his system of values accordingly, and furthermore that he should accept his disability as a reality, then here there is a vital task for all who take part in the care of the handicapped. To be privileged to help the handicapped, to see not what they lack but what qualities they possess and/what they can achieve, in short to teach them to see that life can be meaningful for the handicapped for, that is a thing which is of inestimable importance.

I hope these views can be a contribution to a better understanding of the less privileged in life.

CONCLUSIONS

For the purpose of clarity, all the tasks listed which come under the responsibility of the National Fund for Social Rehabilitation have been arranged in a systematic and logical order.

However, I should like to emphasis that the personality of the handicapped person is very much an individual and really specific problem which needs to be resolved individually with a lively imagination and certainly not with legal texts and regulations.

I wanted to mention this so as to stress that, side by side with this document, which is necessarily theoretical, there are a great many things, which can only be of a pragmatic and practical nature, that can be done.

THE ROLE OF THE FAMILY IN THE REHABILITATION OF THE DISABLED CHILD

Henry SCICLUNA*

ABSTRACT

The family is the basic unit of society and as such plays a determining role in the rehabilitation of the handicapped child as a stabilising and co-ordinating factor. The acceptance by the family of the handicapped child involves the family's responsibility to rehabilitate the child and to integrate him into society.

From medical rehabilitation which is the starting point of the process, through the educational and vocational training of the disabled child, the family is constantly involved in a whole series of relationships with the other participants in the process as the co-ordinating link between the services and the motivating force behind the disabled child.

The family's role goes beyond its participation in the process as such and within parental organisations can help to bring about a change in the mental attitudes of society for an easier acceptance of the handicapped person.

1. THE FAMILY AS INITIATOR AND PROMOTER OF THE REHABILITATION PROCESS

1.1. REHABILITATION - A LONG AND CO-ORDINATED PROCESS

Throughout the centuries the family has been the basic unit of society whatever the political or religious system in force. We can safely assume it will remain so.

The child [1], handicapped or otherwise, grows up and develops within the family structure and becomes to a great extent what his family makes of him.

The future of the handicapped child, just as that of the normal child, depends therefore on the attitudes and choices of the family in which the child is brought up. With the handicapped child, the influence of the family is even greater because the future of the child can be ensured only through a long and complex process of rehabilitation.

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[1] This paper deals exclusively with the handicapped child. The family, however, plays an equally important role in the rehabilitation of disabled adults (for example, the moral support of the wife in the rehabilitation of her husband who is adventitiously disabled).

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In one of the earliest Council of Europe recommendations [2] rehabilitation is defined as "all measures designed to prepare a disabled person mentally and physically to take up or resume a normal place in the community within the limits of his capacity whether in the employment field or at home." And a 1975 glossary [3] defines it as a "continuous process designed to maintain, increase or restore the disabled person's capacity to pursue a normal activity."

An analysis of these definitions reveals that rehabilitation
- is a single continuous process concerning a single individual;
- involves a variety of measures -medical, educational, vocational, occupational, employment and social- and aims at the fullest possible social integration.

The process is therefore
- a long process extending from infancy or onset of sickness till social integration;
- a co-ordinated process where each participant -doctor, teacher, vocational adviser, employer- is involved not only with the aspect mostly concerning him, but with the whole process.

These two basic characteristics -continuity of the process and co-ordination of the various aspects- bring out clearly the role of the family as the initiator and promoter of the process, and the link between the various measures.

It is a role only the family can achieve through the stability of its structure: so much so that where the natural family ties cannot be fully maintained, a recommendation on the rehabilitation of the mentally disordered [4] recommends to the member states to "provide a system of medical and educational institutions for mentally sub-normal children, preferably retaining the family background. Where institutional care is necessary, ensure that it has a family structure in order to encourage stable links of affection between the child and the mother-substitute, at the same time taking all necessary steps to maintain natural family ties where possible ..."

1.2. ACCEPTANCE AND RESPONSIBILITY

The family is normally the first and often the only one to know of a disabled in the family, particularly in the case of a congenital disability. It is therefore principally incumbent on the family to accept the child as an individual or reject it. No amount of legislative or other control can change that situation. However, its acceptance as a member of the family implies something more than love and affection. The existence of a handicapped child in the family is to be faced with realism and courage, and its acceptance becomes meaningful only when the family as a whole is resolutely decided to take recourse to all the necessary measures to rehabilitate the child physically, mentally and socially.

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[2] Recommendation on policy on the rehabilitation of the Disabled (adopted May 1950; revised November 1958)

[3] Glossary and List of Principal Terms used in the Rehabilitation of Disabled Persons, Council of Europe, p. 23, Strasbourg, 1975

[4] Adopted September 1955; revised May 1960.

Such a decision has far-reaching effects on the child, on the family and on society in the sense that these three components of the public are brought into the process of rehabilitation and linked together throughout it.

2. THE FAMILY AS THE LINK IN THE REHABILITATION PROCESS

2.1. THE FAMILY-DOCTOR RELATIONSHIP

A 1969 Resolution underlines the fact that rehabilitation is a process "in which emphasis at the beginning is on the medical aspects and at the end on the work aspects".[5]

This means that the first and perhaps most important relationship in the process is between the family and the doctor.

In fact, the doctor is often the first and sometimes the only person to know of a disability in the child; and in such a case the responsibility of starting off the rehabilitation process rests solely with him. The initial collaboration between them is in any case the starting point of the rehabilitation process and the first link with the subsequent measures needed. The success of these measures will depend to a large extent on the physical and mental capacities which medical rehabilitation manages to maintain and improve.

The contribution of the family and the doctor at the start of the process comes out clearly in a recent Council of Europe report on the identification of disabled people [6]. The report stresses the importance of the doctor's co-operation in identifying disabled persons and in the provision of following measures, particularly measures not taken by the doctor himself, but states at the same time that "it was the disabled person himself or his family who played an essential role when it came to identification and registration and also consequently when it came to rehabilitation measures being made available as early as possible."

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[5] Resolution AP (69) 4 on the training of personnel concerned with rehabilitation

[6] Identification of Disabled Persons, Strasbourg, 1977

The significance of the doctor-family relationship is therefore not limited to early identification, diagnosis and treatment. Its importance goes beyond the medical stage and lies in the link with the subsequent services - a link which the family ensures, together with all those concerned with the rehabilitation process.

2.2. THE FAMILY WITHIN THE PROCESS

The role of the family as the link in the rehabilitation process and its relations with the other participants in the process is stressed in a number of resolutions.

A recommendation on the means of locating disabled people [7] calls for an information system so that "the disabled themselves, then family, employers and employees and the general public are sufficiently aware of the measures available for rehabilitation and what it can achieve." This request is echoed in a 1963 resolution [8] which considers as one of the tasks of health education "to instruct the families of the handicapped of the existing possibilities of rehabilitation and to develop their comprehension of the needs of handicapped people." The emphasis is on supplying information to the family but not limited to it. A recommendation on the educational aspects of rehabilitation says that "family doctors, school medical officers, social workers and teachers should be aware of the possibilities for further physical and psychological examination and treatment and special education for handicapped children."

Consequently, each person dealing with the rehabilitation process is to be aware of all the facilities available but it is the family that remains the central figure assuming the responsibility for the process.

Thus the doctor-family relationship expands and moves along the process to include the other participants.

The 1950 recommendation [9] stresses that "it is of the utmost importance to combine as early as possible medical treatment and the various stages of medical and occupational rehabilitation."

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[7] Recommendation on the means of locating disabled persons who, although in need of rehabilitation have not so far had access to modern methods of treatment and training (adopted in May 1958)

[8] Resolution AP (63) 2 on health education with regard to the rehabilitation of physically and mentally handicapped persons

[9] See footnote 2.

The role of the parents in the resulting co-ordination is set out in a recommendation on the rehabilitation and training of physically disabled children and young persons in relation to their placing in employment [10]. It recommends the necessary steps "to ensure that the vocational guidance of adolescents is carried out by a team which should include a vocational guidance adviser, a doctor and a social worker. The parents should be associated with this process ..."

Another recommendation on the educational aspects of rehabilitation [11] proposes ordinary schools whenever possible but strongly recommends that where special schools are unavoidable "contacts between the special school and the family of the handicapped child are indispensable; the interest of the family should therefore be stimulated in the work of the school."

2.3. THE FAMILY AND THE DISABLED CHILD

From acceptance through medical rehabilitation up to educational and vocational training, the family is the driving force behind the process. It is however a process where the protagonist is the disabled child himself; and the process can succeed only if the disabled child can be successfully motivated to being rehabilitated. An outline plan for a 1979 Council of Europe study on the motivation of physically disabled people for rehabilitation, mentions inter alia the introduction of motivation for congenitally physically handicapped persons when they are capable of understanding the importance of being rehabilitated and for adventitiously physically handicapped persons at the onset of the disability: in other words, at the earliest time possible.

Motivation appears as an important element since the first 1950 recommendation on policy on the rehabilitation of the disabled [12] The recommendation states that "in this process, the active and continuous co-operation of the disabled person himself is essential." A 1963 resolution on health education [13] stresses the importance of encouraging "the handicapped to co-operate actively in their rehabilitation." This encouragement to make an effort, the motivating force to achieve social integration is the duty of every participant in the process of rehabilitation -doctor, teacher, social worker; but none can give it better and be more effective than the family which is the stable element in the child's life and the co-ordinating factor in his rehabilitation.

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[10] Adopted April 1951; revised October 1957

[11] Adopted April 1955

[12] See footnote 2

[13] See footnote 7

2.4. THE FAMILY AND SOCIETY

The family predominates in the rehabilitation process; but the rest of society plays its part. The mental attitudes of the other participants in the process, of society in general and of the state determine the extent and degree of motivation which the family can effectively inculcate into the disabled person.

The whole infrastructure to permit a successful rehabilitation process escapes to a great extent the control of the disabled family. The attitude of employers, the problems of accessibility to public and private buildings, and particularly housing, the possibilities of leisure activities for disabled people are but some of the problems in which the family is often helpless.

Even in this respect, however, the family can still achieve much at both the individual and the collective level.

The family that accepts the responsibility to rehabilitate the child and consequently to notify the disability, in the long run helps the state in assessing the extent of the problem. The 1977 report on identification states that such notifications "could also make for a more judicious and broader approach to the problem on the part of the relevant organisations and consequently better planning."

Families organised in parental organisations can be a tremendous force in achieving results and changing mental attitudes. The Council of Europe which is an inter-governmental organisation, has, in the past 28 years, addressed to its European member states numerous recommendations and resolutions covering all aspects of rehabilitation. This it has done in the knowledge that the state, as representative of the whole of society, has the responsibility to acknowledge the right of the disabled to rehabilitation and to see that this right is fulfilled.

The European Social Charter, signed and ratified by eleven European member states [14], declares in Article 15 that "with a view to ensuring the effective exercise of the right of the physically or mentally disabled to vocational training, rehabilitation and resettlement, the Contracting Parties undertake:

1. to take adequate measures for the provision of training

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[14] The Council of Europe member states that have signed and ratified the Social Charter are: Austria, Cyprus, Denmark, France, the Federal Republic of Germany, Iceland, Ireland, Italy, Norway, Sweden, the United Kingdom. Belgium, Greece, Luxembourg, the Netherlands, Switzerland and Turkey have signed but not ratified it.

facilities, including, where necessary, specialised institutions, public or private;
2. to take adequate measures for the placing of disabled persons in employment, such as specialised placing services, facilities for sheltered employment and measures to encourage employers to admit disabled persons to employment."

The Council of Europe has nonetheless elaborated a policy which does not give to the state the monopoly for rehabilitation services but the general control and supervision. The 1976 resolution on detection [15] sums up admirably the role of the state and the contribution of voluntary organisations when it calls on governments to "carry out regular evaluation of rehabilitation facilities provided by the appropriate organisations so as to have an overall view of the number, nature and structure of rehabilitation establishments, services and programmes, of the rehabilitation personnel needed and of the effectiveness of what is being done" and to "provide better opportunities for co-operation between all identification and rehabilitation services whether public or private and favour the exchange of information on people in need of rehabilitation facilities with a view to ensuring the continuation of these facilities and avoiding duplication of work..."

The outline plan for the study of motivation for 1979 includes amongst the points listed, the role of voluntary bodies, that is how and to what extent can voluntary bodies help in providing encouragement to disabled persons.

Parental organisations fall well within the scope of this study and have an important role to play both as a pressure group and as an experienced sector of society. It is the family that principally provides the disabled child with motivation for rehabilitation. It may be added that the family needs in its turn to be motivated to play its role in the rehabilitation process and this is the duty of society, of each and everyone of us.

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[15] Resolution AP (76) 3 on the identification of disabled persons.

Disability in the family in the GDR

K and U Renker and W Presber

Many facets, issues and objects of rehabilitation may be brought up during a discussion and the tasks facing private organisations, governments and society, or individuals and groups can be outlined. But always the family is the group most concerned in society and it is the family which brings to bear a determining influence on the life of a disabled.

The family enjoys special support under conditions of a socialist society and the constitution of the German Democratic Republic clearly reflects this.

It says in paragraph 38:

1. Marriage, family and motherhood enjoy the special protection of the country. All citizens of the German Democratic Republic shall have the right to respect, protection and promotion of their marriage and families.
2. This right shall be guaranteed by the equality of men and women in marriage and in the family and by public and government support given to citizens to streng, then and develop marriage and family.

   Large families and single parents shall be shown care and be given support by special measures taken by the socialist state.
3. A mother and her child shall enjoy special protection by the socialist state. Maternity leave, special medical care, material, including financial, support will be made available at childbirth and a maternity bonus shall be paid.

The GDR Family Code stresses the special importance of the family. On over 3oo pages, this code provides a comprehensive legal framework, covering all aspects of marriage and family life in the German Democratic Republic.

Such specific family features as special emotional links, durability, stable relationships, a high degree of intimacy, the certainty among children to be secure, bring about a special social relationship between parents and their offsprings. This feeling of family love is a most important catalyst which contributes to create and enhance the emotional, spiritual and intellectual surroundings of children. Very often the role of parental love is underestimated in its relevance for the development of children.

Processes of material and intellectual development in socialism influence the family which assumes a new dimension in turn and affects social development. The strenghtening of intra-family relationships serving the continuation of the human race is an objective requirement in socialist society. In this respect, society places great demands on families. This is borne out by growing expectations of people as for the substance of life in the family but also by growing demands on society by the families.

This situation brings about special conflict in the GDR. Shortage of labour has meant full employment for the last 3o years, i.e., there was not a single unemployed. This calls for possibly full and continuous employment of women on the one hand but for increasing birth rates on the other.

But, first and foremost, full employment of [illegible] is to be considered positive insofar as it enables [illegible] to practise their right to equality.

All over the world there is no dearth of literature on the influence of demographic factors on working women, on the effects of work on birth rates and on possible social control of this development. It is generally considered that there is a causal relationship between birth rates and the percentage of women working. As a rule, the lack, or the insufficient amount of, services and infrastructural conditions provided, scarcity of child care establishments and an unchanged division of labour in the family lead to an overload of work for women. In general, this applies to nonsocialist countries.

By a generous political programme of social welfare, the state tries to meet the large expectations of families and their challenge to society. The outstanding features of such programmes are typical of socialist states. I would like to mention only some as they have been taken in the GDR.

To name just a few, we have free medical treatment and hospitalisation, free supplies of drugs and all types of aids required, free hospital treatment during pregnancy disturbances and for childbirth (all children are born in maternity wards), free reconvalescence trips during pregnancy and after birth, considerable payments by the government and cheap loans for newly-weds and a paid maternity leave of six months, one year paid leave after birth of second child. A mother may also stop work for a total of three years without losing her job, maternity benefits to the tune of 1 ooo marks for each child born, there are free crêches and kindergartens, a day a month off on full pay for household duties for married women and other women with children to look after (such as disabled family members), free marriage guidance and sexual consultation services, general free schooling also of course, for disabled children up to the tenth form, generous scholarships for attending universities and colleges for the disabled, too.

As we see it, these general remarks on the family and on general care for the family by the state as applying to the GDR have to be made so that it will be possible to understand special problems.

In the GDR, this generous support for families, which is even more generous for larger families, is provided by the government as a matter of course and it also includes families with one or more severely disabled members. In this country, there is a network of marriage and family guidance, of which marriage and sexual guidance forms the medical subdivision. These consultation centres influence sexual and ethical education, sexual development, selection of spouses, the wish to have children, and they also provide advice on the most favourable time for the first and any other children. At the same time, there is a network of genetic advisory centres working closely together with the marriage and sexual guidance centres. Termination of pregnancy is also counseled to prevent the birth of children with serious genetic malfunctions.

Initially, I would like to mention the contents of some legal provisions that make life easier for such families:

- rehabilitative holiday treatments for seriously and very severely disabled children,
- in cooperation with public organisations, seriously and severely disabled people are included in plans for holiday and leisure,
- support for organised sporting activities by the disabled,
- establishment of day centres for uneducable and severely mentally deficient children and youths who are able to profit from special training,
- establishment, on a weekly basis, of centres for uneducable and severely mentally deficient children and youths who are able to profit from special training,
- creation of homes for disabled children and youths who fall into the same category.

We just enumerated a few opportunities.

The integration of a family into community life is no spontaneous process even for healthy families, but it is fairly complicated for families with severely disabled members. There is a growing awareness of this feature and it is included into the planning of social developments. Tus, a mother of a severely disabled child for whom no creche can be found immediately, is given a certain percentage of her full salary up to one year after childbirth.

We would now like to outline the full range of concern for disabled children, particularly those with severe disabilities.

Let us first come to the share of medical measures.

Some of these disabled children have to see a doctor on several occasions spread over years or they are in need of one or two operations also in the course of several years. Medical rehabilitation is confined to short-time therapy or control measures.

For the majority of severely disabled children the medical part of a rehabilitation programme includes certain regularly-spaced courses of treatment apart from current medical consultations over many years and repeated hospitalisation of various length.

The legal and organisational framework for this work has been established in this country. There is a legal provision for registering all disabled children up to the age of eighteen and this has been abided by. In the GDR, medical care is guaranteed, there is one doctor for every 500 people (the aim is to have one doctor for every four hundred people by 1984). At present, the GDR numbers 33 000 doctors. The number of hospital beds for all types of diseases is sufficient.

Usually, the family doctor look after a disabled child first. He may be a general practitioner or the pediatric chosen by the parents. For children with psychic disturbances he will work together with neuropsychiatrist for children and, in the case of a physically impaired child, cooperation will be sought with an orthopedist. There are special facilities in dispensaria for use by the family doctor and the pediatric. No permanent treatment is given here but there is referral back to continued treatment if that proves necessary, a vital point, because otherwise the family would have to be in permanent contact with too many doctors. For, if there is for instance, a child with a multiple disability or if there were a second child with another disability, three or more doctors and very often three or more centres would have to be consulted for medical advice. If you add the doctors responsible for school children and those for sport fitness evaluations, who also proffer advice and lay down treatment, then it becomes obvious that the most important person to provide medical advice must be the family doctor. He co-ordinates all the necessary steps to be taken, including social measures. This is the only way to live up to his role of family doctor and health officer. This is an important condition for optimum child rehabilitation. And only thus the continuing co-operation of the parents can be kept up, because only long-term treatment promises any success.

A particularly favourable condition in our country is that the family doctor mostly works in an out-patient establishment, such as a general medical centre or a policlinic, or that he is closely allied with such a centre. Here we find specialists from various medical fields in one establishment who may consult each other at any time. As mentioned previously, our legal system provides for the registration of disabled children.

Very often, hospitalisation is needed for severely disabled children and over long periods. Here we trie to maintain permanent links with the parents over the whole course of treatment.

After birth, parents have to get used to having a malformed child or one with severe disabilities, things need to be explained to them, they must be given psychological support, and this also applies to acquired malfunctions. Parents must learn to first recognize their child, and a malformation or lesion to come second. Also, they must come to accept that for the rest of the world, the lesion or malformation will often still come first and the child as a human being will only be seen after that. This is a difficult period but the development of internal readiness takes time. This development, however, can only be brought about by permanent contact with the child. The danger of such readiness not growing up increases with the frequency and length of separation of children from their parents. A longer separation may mean loss of this feeling, in particular when there are other, healthy, children or when such are born into the family.

In the GDR, by introducing new regulations for temporary dismissal from hospitals, the former strict rules were abolished. Those children who do not have to remain in hospital will be sent home for the weekend. This serves to maintain urgently needed links between parents and their child.

As for medical rehabilitative work, one of the central issues is that of guaranteeing its continuity, also outside the hospital. And this is by far the major part. It is not sufficient to employ therapists, even the most highly developed country could not cope with the personnel requirements. It is inevitable to involve parents in this part of medical rehabilitation and the plan of treatment.

The necessary systematic and repeated training of parents who will have to do home exercises is organised in parent seminars, individual sessions or training courses for which we invite mothers or, very often, fathers. Sometimes mothers come with their children even for an in-patient period at the rehabilitation centre. Responsibilities of the nurse and instructor who work under a doctor are to have frequent checks at short intervals on the way the course is carried out and then to develop continuation methods, taking account of individual conditions.

Of course, much time is spent on looking after severely disabled children. The government, therefore, also looked into other possibilities.

The burden on many families has been considerably eased by the creation of crèches, kindergartens and other child care facilities and the setting up of special groups of disabled children there, as well as in special institutions for the disabled, such as day centres, weekly and residential homes for uneducable children and youths who are able to profit from special training.As we already mentioned,the establishment of more such groups or institutions is one of the focal points in the social welfare programme of the GDR government.

Great responsibility for every disabled child devolves on society, too. In the German Democratic Republic the protection of health and of the capability to work,including rehabilitation of those who require it, has also been enshrined in the constitution. As a matter of principle, children who are severely disabled are not better off in the family, but there is no dearth of cases where transfer to a home will be preferred to growing up in the family. Society thus attempts to replace a family atmosphere. Quite generally, the government helps by taking measures to improve the overall situation for the disabled in society.

On the other hand, life in the family can only be shaped by its members whereas society is co-responsible for conditions of development in all families.

The socio-economic order in a country is determining the place of human beings in society and in the family. Equality of women has a special effect on life within the family, whereas the social commitment by all members of the family is of a general nature. Disabled family members bring about particular conditions. The awareness of parents and children provides strongly different reflections of the burdens imposed by serious physical or psychic impairments which may lead to changes required in the life led by the family so far. In the GDR, there are many examples of how mothers and fathers cope with such often very difficult conditions and how parental love makes possible the very best development for such children under their particular conditions.

Most of these problems are eased by the relationships between spouses, in a socialist society. These can be described as follows:

1. These are relations built on mutual love and respect as well as on complete equality which is to play its part in the development of both into equal personalities with equal rights and duties.
2. Bringing up of children in the spirit of socialism. In this, parents work closely together with socialist education facilities (this includes the capacity by parents to raise children and in general a feeling of responsibility for their upbringing.)
3. Bringing a socialist way of life to prevail which also reflects the stable nature of family and marriage relationships. This is also to include the ability on behalf of family members to cope with difficulties in a responsible way that looks ahead.
4. The ability to responsible family planning, to decide themselves when and how many children to have, with orientation toward a three-child family.

5. Use of the development prospects made available by society by both spouses. Awareness of the support coming from society to build up family life and to overcome difficult periods.

Assistance by society through supportive health and social services as well as special educational facilities is appreciated as natural by the parents concerned. Therefore, in the GDR, great emphasis is placed on good relationships between these services, school and parents in the case of severely disabled children.

Educational rehabilitation is an essential link in the overall system of rehabilitation. For a disabled child training and education at school is just as important than for healthy ones, if not more. For the former, the chance of finding an appropriate profession or trade is even more dependent on his or her education and the success of the supportive educational measures received during rehabilitation.

At present we are building in the GDR schools for physically handicapped children at a rate that will allow us to give all of them a full education in special schools in future.

Youths suffering, for instance, from muscular dystrophy, who can not be sent to school daily, will be given lessons at home and a teacher comes to see them, but these are relatively few exceptions.

Our educators hold the view that special schools for the disabled can offer much more favourable conditions than homes, by making available smaller classes and special facilities and technological aids.

Parent-teacher committees in classes and advisory panels of parents at schools establish close links between teachers and homes which will be kept from first to tenth form. These good links do also obtain for schools for the mentally deficient and day centres for those to be given special support.

Already from the 6th form onwards, our special school students are given information on possible professions and trades. Careers guidance is included into effective cooperation among educators and parents as early as possible.

For a greater part of the disabled, finding skilled workers training or taking up studies at a university or college introduces a gradual separation from their families which is in keeping with their age.

We say that the kind of disability is of great relevance for the integration of children into society but also for the position in the family. Children with lesions of the locomotor system have far less difficulty of being integrated into their families and society than those with severe mental deficiencies. But this does not only apply to children but also to disabled adults.

In the last few years, the general attitude towards the disabled has clearly improved in the GDR. Press, radio and television give greater fuller coverage to the disabled and his environment. This significantly improved understanding of society also helps the parents of disabled children to cope with the child and their tasks.

Let us summarize:
Disabled children should only be sent to hospital, boarding houses, or permanent homes if that is in the interest of the child concerned better medical, educational or social care, support and training.Links with the family should then be maintained. For us, putting up children in homes in the interests of the parents is the exception. When speaking of parents have to face that intolerable burdens in bringing up severely disabled children, one should ponder the mistakes that have been made in helping them.

After the full circle of rehabilitative treatment including medical, educational and occupational rehabilitation has been covered, it is mostly comparatively easy to separate children from their homes by gradual inclusion into teams of apprentices, students or workers. This is more difficult with very severely disabled people whose very disability rules out any prospect of working in a factory, but who will be taking up work in sheltered workshops run by the country's health system. In the main, their contacts are limited to those with other disabled.

We are happy to note the growing number of marriages among the severely and very severely disabled. This trend is favoured by wheel-chair accessible flats of which a growing number has been built in the GDR in the course of the last few years. We mention this here because we shall have to face new family problems, so far unknown to us in that dimension. These young couples of which one partner is severely disabled or where both are severely or very severely disabled, very often want to have children. They fight for a child of their own, or for an adoption. We not, that social integration of the disabled in the GDR is making good headway that could be described as almost revolutionary.

The same holds for modern socialist relations between the sexes which are having their effect on the sexual relations between disabled men and women and their relationships generelly.

We would like to point out an issue which is still causing us concern, i.e., the separation of the mentally disabled from their homes. They are given help in day centres and to a great extent there is an adaption to life in society. Between the age of 14 and 18, they will be transferred to sheltered workshops where a certain measure of vocational training is given and which may lead to permanent employment there or in the sheltered section of an enterprise. Only 2o years ago this amount of support would not have been given and after the death of their parents, these young people would have been sent to a psychiatric hospital for care. Today, this is no longer the case, but, on the other hand, they are sometimes unable to lead an existence of their own in society. 12 years ago we began setting up day centres for such peoples and we have now covered most of them. But more and more of the parents ask where these children will go after they die. As a transitional solution, we have established youth rooms or youth wards in old-aged persons homes, where some of these young people, who are given special support, will be accommodated. Factories have made a beginning in providing residential homes and residential communities including care-taking personnel, but a general solution is still by way of such residential communities outstanding. We believe that it is an important issue of which we treated an example. Of course, we might discuss special questions raised by disabilities in, and their influence on the family. There are a good many psychological, social, individual and general matters to be covered. Here we would only like to refer to a sudden and serious disability of an adult family member, i.e., one of the parents. This occurs more and more often, think only of road accidents and their serious consequences. When speaking of the disabled child we have already dealt with the essential provisions of social rehabilitation in the GDR. These and their effects on security also full apply in such a case. In addition, the situation for such a family will be eased in our country due to the fact that under conditions of socialist humanism man is shown close attention and given support on the one hand, and on the other that there is a scarcity of labour. Therefore, enterprises will be prepared to accept a larger number of disabled. These two basic features have meant that we have found a continuously growing readiness by factories to employ disbaled people, apart from the fact that there are statury provisions for that.

Continued employment and in-service training own disabled staff in appropriate jobs and the provision of jobs for disabled people on application, are covered by the GDR Labour Code that became effective on January 1, 1978.

It can be said that in the GDR it is only rarely that a marriage breaks up as a consequence of a sudden disability afflicting one of the two spouses. We attribute the happy continuation of these marriages in mutual love to this attitude in society, to the social welfare measures taken by our government, to the availability of appropriate housing and to job security.

Carrying out the family law also means integrating those families who have to cope with seriously disabled members. Implementation of the right to work and to education for the disabled, too, his integration into social life, and economic security, all these features are basically relevant to the harmonious development of the family concerned, something that has been guaranteed in the German Democratic Republic.

I would like to be permitted one concluding remark, Our subject "Disability in the family" should be extended to cover problems concerning the disabled among his friends. It was Goethe who already referred to friendships as elective affinities, and they very often mean a lot to the disabled. So not only the family but friends, too, need to be urged into action to help the integration of the disabled into social life.

Rehabilitation International also represents a large family, it is an example of friendship among people. We get to know and respect each other, irrespective of race, relegion, nationality and world outlook. The staff of Rehabilitation International are well aware of the aftermath of wars, all too often they had to carry out rehabilitative work then. In the spirit of the WHO programme Disability prevention and rehabilitation today we focus more and more on prevention. We should therefore strenghten our friendship to serve a future world of peace, to struggle against wars, so as to rule out any need for consequent rehabilitative work.

We are happy to work in the family of Rehabilitation International and this great humanist cause rallies our large family of friends.

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Mons. J. Fonrojet

DISABILITY IN THE FAMILY

For many years, the community in France made the family very widely responsible for looking after the disabled. Measures were taken, true, to assist them but they were very inadequate. Some of these measures, the older ones, were based on the idea of assistance: it was mainly a question of providing help for the poorer families; other measures, introduced at the end of the last century and the beginning of this one, were inspired by the idea of reparation and concerned war victims and persons having sustained industrial injuries.

From the end of World War II, however, and for about the last ten years particularly, there has been a radical change in ways of thinking: The need to reach an overall concept of the problems of the disabled was more and more vividly felt. Moreover, the community's need to accept a solidarity effort in favour of a particular category of its members who were among the least favoured, was gradually imposed. This change probably occurred under pressure from the families of the disabled who organised themselves admirably, both to cope with their difficulties and to make the public authorities and public opinion aware of them. It was helped however by a number of factors: medical progress, higher standards of living, etc.

In 1966, the Government, sensitive to the painful nature of certain situations and aware of the inadequacy of the measures taken till then, asked a reflection group to study all the measures to be taken enabling a solution to the general problem of disability to be found. This group's work formed the basis of a substantial change in the legislation in favour of the disabled. It was only in 1975, however, after long discussions, that a law was passed whose provisions regulated the present measures taken for the disabled.

The new system introduced was based on two main points:
According to the first point, disabled persons have rights: rights to the treatment their condition requires; rights to education, vocational training and guidance, employment, leisure; and, generally speaking, the right to social integration.

.../...

According to the second point, it was a national obligation to enable the disabled to actually enjoy their rights and thus it was not only up to the families but also to the State, the local communities, public institutions and social security organisations, and to the public- and private- sector associations, groups and firms to combine their action.

The recognition of the rights pertaining to the disabled and of the need for a national solidarity effort in their favour did not naturally have as its subject and could not have as its result to deny or restrict the main role of the families of the disabled. On the contrary, it placed them in a better position to take up this role, to take it up under conditions conforming more, both to the interests of the disabled person and their possibilities.

The measures taken in the last few years were worked out in close co-operation with the associations of disabled children's parents represented within a National Consultative Council. Almost all the institutions set up to meet the needs of the disabled are managed by the representatives of these associations or with their very active participation.

The schemes currently in operation in France are designed on one hand to prevent the onset of the various disabilities or to screen them at an early stage in order to reduce their effects; and on the other hand, to enable families to cope with their responsibilities when one of their members becomes disabled.

A/ Prevention and Screening Schemes

The prevention and screening schemes are very important and the French legislator has wanted them to form a national commitment. Thus, within the 7th French Plan, currently in progress, a programme of priority operations has been defined; this concerns both the prevention of the difficulties related to pregnancy and childbirth which form the origin of most disabilities and medico-social prevention in favour of children.

.../...

I will not dwell on this type of action however. I will simply mention the guidelines adopted:

The scheme covers three points:

First, improving the knowledge of disability causes. Greater efforts have thus been made for peri-natal research and for data collection on medical and social risks, and on the frequency, distribution and development of the various disabilities.

Second, the information and education both of practitioners and of families – training schemes have thus been introduced, pregnancy and childbirth consultations have been developed; a wide dissemination of available knowledge has been sought through the production of brochures and of audiovisual broadcasts.

Lastly on the monitoring of pregnancies and deliveries likely to involve risks and on the care needed by babies born after a difficult pregnancy. Whether it is a question of the prevention of disabilities or of their screening, new resources have been put into action to provide families with the advice they need, to secure their co-operation, to enable their children to benefit from re-education at a time which might turn out to be the most effective solution.

This type of action has not yet reached its full development, but there are signs allowing one to think that the results obtained are in the right direction.

11. Assistance to the Disabled and to their Families

In conjuction with the development of prevention and screening schemes, provisions have been made to enable the disabled to fully enjoy the rights recognised to them by law. It is the situation of families including a disabled member, whose situation has changed thanks to these measures, that I would now like to deal with.

These measures have been inspired by two concerns:

- to allow the disabled to acquire all the independence they are capable of;
- to secure the maintaining of the disabled, as far as possible, in an ordinary work and living environment.

It goes without saying however that the practical translation of these concerns poses different problems, in particular with regard to the role of families, depending on whether the disabled are children or adolescents, or on the other hand, adults.

1. As regards children and adolescents. These are of course placed under the responsibility of their parents and the public authorities' action is mainly devoted to allowing children and adolescents to take up their responsibilities under the conditions most suitable for the interest of the child and the family balance. Only if the family turns out to be inadequate does the community feel it is entitled to take over from the family.

1.1 The public authorities' action is primarily aimed at helping families to choose for their children the best possible direction, and allowing them to secure for their children the treatment and education best suited to them.

The most difficult problems definitely lie in this field as every case requires a special solution taking into account both the nature and the severity of the child's disability, the suitablility of the family environment and the possibilities offered by the existing facility.

With a view to making decisions on the guidance of disabled children and adolescents, special education commissions have been formed, at local government level, consisting of capable personalities including at least a doctor, representatives of the Government departments concerned (Education and Health) and representatives of the disabled children's and adolescents' families' associations.

These commissions are briefed to render decisions on guidance schemes proposed to them by multi-discipline teams consisting of teachers, doctors, educators, psychologists and health visitors. These teams' objective is to study each case under all its aspects: medical, social, psychological and educational, working in close liaison with the family and the practitioners who have followed the child.

The special education commissions' decisions are imposed both on the schools and on the special education establishments which have to admit any children referred to them. They are not imposed on the parents who are free not to follow the decision and also to choose which school they wish to enter their child for.

The way these special education commissions work - they were set up almost two years ago - has led to a number of criticisms in that it is up to them, and them only, to say whether a child is disabled and to what extent he is disabled, and to recommend a guidance procedure.

There is no doubt however that their formation met a real need for a large number of families that were unable to find their own solutions to the problems posed to them by their child's disability.

1.2 The public authorities then went about making up for the financial commitments that disabled childrens' families have to undertake to see that their children have the right treatment and education.

Wherever the condition of the child or the adolescent justifies his being admitted to a special education establishment, the cost of his accommodation and those charges related to the treatment or training he receives, are borne in full by the Social Security institution or by the State.

If, on the other hand, the child can be kept at home, his family can claim entitlement to a special education grant if the child is under 20 years of age and if his degree of disability is at least 80%. The family can also claim, if applicable, an extra grant if the child's disability is of a nature and severity requiring particularly heavy expenses and if the child in particular needs to have - permanently or intermittently - the assistance of another person.

Moreover, the State covers individual travelling costs of disabled pupils and students to schools and universities, made necessary through their disability.

.../...

The cost of group transport of disabled children and adolescents to medical/educational establishments operating as boarding or semi-boarding schools is borne by the organisations responsible for the children.

1.3 The public authorities, lastly, have attempted to promote the development of facilities which, through their design and their location on the national territory, allow disabled children or adolescents to benefit from the treatment and education they need while remaining close to or within their family.

In this particular field, a certain awareness of the often very damaging consequences of too long a separation between the family and the child has led to a limitation in the setting up of specialised establishments and to developing new rest and treatment schemes.

A substantial effort has thus been accomplished first, to welcome as many disabled children and adolescents as possible within schools open to all children and in forming adaptation classes or specialised education sections within such schools. Furthermore, recommendations have been sent to the commissions responsible for the guidance of disabled children with a view to limiting entry to specialised establishments to severely disabled children.

Lastly, a wider coverage by the specialised schools has been aimed at. Emphasis has been laid on day boarding schemes, establishments have been urged to limit their recruiting to a limited geographical area. Lastly, measures have been taken to encourage frequent trips by children back to their homes.

In conjunction with this policy, a number of services have been formed in order to provide assistance to families keeping their children at home. These services include:

- the assistance of family workers if the mother has to be temporarily away from home;
- the formation of temporary assistance and treatment services;
- the assistance of home helps;
- the opening of kindergartens to disabled children in order to free the mother at

certain times of the day or of the week;

- the formation of temporary rest homes allowing disabled children to be entered there for short periods;

- the formation too of home treatment and education services.

These services however are currently not expanding much due to a shortage of suitable finance and to the lack of appropriate regulations.

In most cases, they only owe their existence to funds injected by the disabled childrens' families' association or to organisations receiving local government aid.

True, one could hardly consider that all issues faced by disabled children's families were solved. These often remain due to the lack of sufficient information from the families involved in taking over their responsibilities. Furthermore, too often families do not have the possibility that many of them would like to have of keeping their children at home. The system set up in the absence of people to watch children, both very cumbersome and very exacting, doctrinal oppositions on what is required by the disabled child's full physical and mental development have not disappeared; and a number of striking inconsistencies still subsist in terms of taking over the children and taking over their accommodation and education expenses depending on which particular type of establishment they have been referred to.

Although for many of them the above remarks are not groundless, nevertheless in practice there has been a very substantial improvement of the situation of disabled children in the last few years in France.

2. The policy followed in favour of the disabled does not only concern children and adolescents, but also disabled adults. The effort asked of families can not be in their respect of the same nature as that required of them in the case of children or adolescents. True, family solidarity obviously does not cease just because the disabled person grows up to be an adult and no longer an adolescent. It is quite clear, however, that it cannot act with the same force for obvious reasons which are connected both with the tiredness and anxiety felt by parents as they grow older themselves and are faced with the very heavy burden represented by a disabled adult, from the material and psychological

points of view.

The wish to enable disabled persons to enjoy all the independence they are capable of could not be accompanied by a policy leaving it to families to care for disabled adults.

The authorities' action in favour of disabled adults has had three main objectives.

2.1 Measures have been taken, first, to provide disabled adults with a minimum level of resources.

As soon as any disabled adult's disability rate is at least 80% and his resources are lower than a certain ceiling, he can, at his request, obtain benefit known as a disabled adult benefit, his family being exempted, from a means test.

It is up to commissions set up at local level to assess the severity of the disabled person's disability and his entitlement to the disabled adult's benefit.

Any adult disabled person who is working and whose disability rate, assessed by the above-mentioned commissions, is at least equivalent to 80%,is also entitled to the benefit of deriving from his work a minimum level of resources, this level varying according to whether the disabled person is working in normal production conditions or in a protected environment.

2.2 Furthermore, a substantial effort has been made to offer disabled adults accommodation possibilities if they do not live with their family or do not have their own home. There is currently a wide range of establishments designed to accommodate disabled persons and within which they benefit from the assistance of a specially trained personnel. If they cannot provide for their own accommodation, its cost is taken over by the community and they are given a minimum amount of financial resources.

Their admission to a disabled persons' hostel is recommended by the commissions I referred to earlier and which are known as vocational guidance and placement commissions.

2.3 Lastly, in order to enable disabled adults to use the services of another person when their assistance is needed, they may be granted a benefit known as a compensation benefit.

All these measures represent a substantial financial effort on the part of the community whether it be the cost of the benefits paid to disabled adults, or the accommodation costs borne by the community.

In spite of the extensive efforts made by the community, one cannot say that disabled adults' families are thereby relieved of all responsiblity in connection with their adult children.

The keeping of disabled adults at home, like that of children and adolescents but in a certainly more traumatic way, faces the stumbling block of the disabled adult's impossibility of having a certain amount of treatment on a full-time basis.

Cash benefits are virtually the only answer given to the problem of disabled adults living at home. Such benefits cannot allow them to have another person with them on a full-time basis.

The issue is not only a financial one.

Resorting to individual solutions is proving in this connection to be very often unsuitable. The unavoidable absences of the other person - holidays, week-ends, sickness - in most cases put the disabled person in a difficult situation.

Furthermore, the training which has to be given to other persons assisting severely disabled adults is currently being questioned.

The inadequacies of the French system of assistance to the disabled are well known by the French public authorities.

The measures implemented since 1975 have formed an important stage - but only one stage - in taking into account the disabled's needs.

Among those action schemes that must be undertaken very soon, priority must be given to those making it easier for disabled children to remain within the family home and for disabled adults to remain in their chosen environment.

In this connection, the convention currently being held here in Brighton and the effort of joint studies and comparisons of the policies followed by the different countries involved have come at a particularly appropriate time and I should like to conclude by thanking the convention organizers.

Seminar 1

INFORMATION AND COMMUNICATION
Chairman: *Air-Commodore D. F. Rixson, OBE, DFC, AFC*

Isolation in the Family Environment—the Role of the Provincial Newspaper
Lt. Cdr. F. A. Saunders, AEA, RD, RNR

Problems of Communication in Chronic Illness
M. Bury

INFORMATION AND COMMUNICATION
Chairman: *Mr. C. J. Carey, Dip.S.Sc., MBASW, MISW*

Disabled Information and Advice Line (DIAL)
Mr. John Grant

Breaking Barriers to the Employment of the Handicapped
Hilary Schlesinger

INFORMATION AND COMMUNICATION
Chairman: *Cllr. F. Long*

The Difficulties of Information Provision for the Disabled and their Families
Julia Spicer/Sheila Cooper

INFORMATION AND COMMUNICATION
Chairman: *Prof. K-H. Renker*

The Information Services of Rehabilitation International
Barbara Duncan

Generalised Control and Information System for use by the Handicapped
Chris Evans/Julia Howlett

FREE PAPERS
Chairman: *Dr. M. Naomi Wing, MB, BS, DPRM*

Air Travel for the Disabled
Mrs. Zipora Brun

U.S.A. Independent Daily Living Program
Mr. David Williamson

ISOLATION IN THE FAMILY ENVIRONMENT: THE ROLE OF THE PROVINCIAL NEWSPAPER

Pat Saunders*

ABSTRACT

1. The improved status of the disabled person has brought increased responsibilities for himself and demands for a fair share of the community's amenities.

2. Isolation within the family unit is aggravated by poor communication with the world at large.

3. Little of the media is devoted to the interests of the disable. There is no regular material in Britain in either the national or the provincial newspapers.

4. A handicapped person will be happier if he becomes an expert in the disabled way of life.

5. Setting up a regular newspaper article for the disabled will involve consideration of:

    (a) A sponsoring group.
    (b) An information resource centre.
    (c) Spectrum of readership.
    (d) Geographical coverage.
    (e) Title and caption.
    (f) Style.
    (g) Content.
    (h) Layout, drawings, photographs and cartoons.

6. Feed-back from readers.

7. Method of working.

8. Social implications.

9. Conclusion

    (a) There is a gap in communications needing urgent attention.
    (b) There is no overlap with existing publications.
    (c) Influences public opinion at the point where decisions are made.
    (d) Rapidly becomes a valuable social service for the disabled.

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* R.A.D.A.R., S.I.A., A.D.P., D.I.G., M.S.S., B.L.E.S.M.A., S.E.Hants CHC.

Because the position of handicapped people in the community has improved greatly in the last few years, society is becoming aware:

(a) That disability need not be equated with illness. The rapid growth of sports associations for the disabled demonstrates this.

(b) This enhanced position has brought to the handicapped increased responsibility for their own affairs, increased participation in activities formerly reserved for the able-bodied and arising from these, increased demands for a fair share of all that society has to offer.

A person who is the only disabled being in a family group often feels isolated from the world he knew before disablement yet he cannot identify with his new society. This feeling is aggravated by a lack of everyday communication.

The disabled are not getting a fair share of the media - newspapers, magazines, TV and radio. When you become handicapped you enter a whole new world of strange jargon, equipment, sports, hobbies and social relationships - in fact it is much the same as becoming a golfer, yachtsman or vegetarian. Whatever your new interest is, you will enjoy it more if you spend the rest of your life becoming an expert at it and this applies no less to being disabled. The media should provide part of the means for you to become an expert.

No national newspaper has a regular section devoted to the disabled, yet there are 3,000,000 readers. In both national and provincial papers are regular weekly features on everything from chess to antiques. There should be a weekly column for the disabled, written by the disabled, in every provincial newspaper in Britain. At the time of writing, the weekly article which I write for the Portsmouth "News" is the only regular 'disabled' article in contact with the general public.

The author of such a column has immense advantages if he himself is disabled. The purpose of this paper is to outline how a disabled or even an able-bodied person can set about writing a regular article for the handicapped readers of a local newspaper. The following will need consideration:

1. The creation of a bank of information.
2. A pressure group to convince the editor of the need.
3. The spectrum of readership.
4. The geographical area to be covered.
5. A title and caption.
6. Style
7. Content.
8. Layout drawings, photographs and cartoons.

Only after you have immersed yourself in a subject for a long time can you write an article starting with only a blank sheet of paper.

Most popular writing is the result of paraphrasing, amending, condensing, and if it's a DHSS leaflet, translating other people's work. There is no shame in this; the skill lies in selection and presentation in a form attractive to the public. So a resource bank has to be built up by writing for catalogues, writing to individuals, associations, social services, Community Health Council, Community Care council and agencies of local and national government. The writer should be in membership with a number of national voluntary associations, all of which are sources of information. The Disabled Living Foundation and the King's Fund also provide regular resource material. A filing system is very necessary both for stored material and live correspondence and it may be wise to take advice about setting up a home-based work station. A small library of relevant literature is essential.

Editors are hard men to convince in a world of competing claims for expensive news-space. To persuade them of the need you have to have a powerful pressure group to present your case - a city council, a community health council, a trades union or a well-known local voluntary association for the disabled. In the first instance the writer will have to persuade the pressure group that the article is badly needed and that he is able to do it. If possible set up a small pilot committee involving the newspaper staff. With careful management they will become convinced it was the paper's idea in the first place.

For whom should the article cater? With the physically disabled should there be the blind, deaf, speechless and the mentally handicapped? Certainly the article will be read by the caring relatives and caring professionals. What provision should be made for the young, the very young? Growing old brings nature's disabilities so the senior citizens need column space. Success really comes when the article is read by the general public. Only this way can you influence public opinion. Influencing public opinion is one of the most important functions of any newspaper.

The geographical coverage will depend on the number of regional editions printed by the paper and to what extent the articles contain local news. If the paper covers places fifty miles apart selection of local material is still possible but it needs care and constant monitoring to make sure every area has a fair share.

Readers of popular newspapers like that which is familiar. A regular column should appear on the same page of the paper and on the same day each week. An eye-catching caption embodying the title, is normally a panel covering two or three columns and would be a good design exercise for an art class. The layout and sub-titling system should also be fairly constant. This 'familiarity' aspect is an important step towards getting your readers turning eagerly to your article to see what you have to say this week.

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Pat's Piece

Make a date with Pat Saunders in The News every Thursday. In lively, colourful prose, he writes for the handicapped — and for those people caring for the disabled in the community.

Many readers are writing to Pat and he will answer all letters as soon as he can. Keep them coming — he is pleased to hear from you, and will try to develop your ideas, suggestions, and stories in his column.

Style requires careful consideration. The majority of readers of provincial papers are readers of the tabloid daily papers and you are writing for the majority. Your style must be a simple, 'chatty' easily read form. This is quite difficult and usually every article has to be written several times - once to put your thoughts down, once to put it into simple 'journalese' and maybe a third time to get it the right shape and size. However this requires time and patience rather than expertise and most handicapped people do have time. The disabled and their caring relatives are a microcosm of society containing all ages and degrees of literacy. Your writing must be liked by the majority, and tolerated kindly by the remainder. Humour is very important both in the text and in cartoon form.

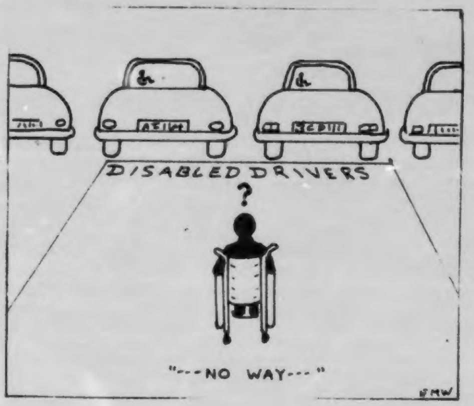
I often think how lucky I am. Only a few days ago my bedroom was filled with attractive young girls!

They had come from Southsea for me to talk to them about access for the disabled. Since that inaccessible shelf or light switch is part of the problem, I invited them home.

And if it had to be the house, why not the . . . anyway, it's my office, too. The girls were doing a project on access, and they will let me know their findings and ideas.

One question set me thinking. "Why," asked one girl, "Is there an access problem now — wasn't there always one?"

Of course, there have always been access problems for us, but ten years ago, they were accepted by the disabled and the community as inevitable, in the same class as colds in the head or Income Tax.



Content is a matter of selection from an over-abundance of material. Careful reading of national and overseas 'disabled' magazines and literature will highlight trends which should be followed. For the majority of handicapped people in your area your weekly column will be the only regular source of information. It must be accurate, simple and up-to-date. Your responsibility is to decide how far accuracy can be sacrificed in the interests of simplicity. Many disabled people do not know their rights under the law and even more are unaware of changes. Not enough is known about new equipment, social services, social security, DIY aids, hospital boards, Community Health Councils, new books, local disabled club activities, holidays, education employment and sport. Local experts can be used to write 'help' articles on problems common to many disabled - e.g. keeping warm in winter, pressure sores, mobility, house modifications. When the writer is established, he should then start trying to influence public opinion about matters of common interest - access, care attendance, education, employment, transport and public attitude. Interviews can be made with influential people whose decisions can effect the lives of disabled people. After a few months the feed-back from readers will make the column partially self-generating.

Meeting a weekly dead-line may, depending on the degree of disability of the writer, be a burden. This can be avoided by working at least six weeks ahead; at any point in time, two finished articles should be with the editor, and four with the writer in varying stages of completion. That way the writer is never in a position where he has to write - in fact a week off causes only a minor hiccup in the production line. Variety can be introduced by using other writers. If the regular writer is handicapped, he should wear his disability proudly and always identify with his readers.

The author of a 'disabled' column is not an expert; he is an interpreter of the experts to the common man; he is a man who knows the experts and is known by the experts. He gives information but more often he tells where the information is to be found. It may be thought necessary to set up a panel of professionals behind the writer - a doctor, nurse, physiotherapist, O.T., D.R.O., social worker, or home help organiser. The writer will need to call on a panel member for advice but rarely; the panel may have a secondary function in meeting occasionally to comment on the column.

The newspaper editor and the column writer should appreciate that a weekly article for the disabled rapidly becomes a social service which cannot be ignored; already this year I have answered letters from several hundreds of people, the majority of whom were seeking solutions to a wide range of problems. For many readers the act of writing to the newspaper is sufficient to break the wall of isolation. From this the newspaper gains little except a reputation for helping the under-dog; the writer gains hundreds of friends. The weekly article becomes an exchange point for things (wheelchairs etc.), ideas, people (who volunteer their services) and needs. The writer spends much time putting those who have a need in touch with those who have something to give. He should accept the many invitations that he will receive to be in honorary membership with local voluntary societies as the regular supply of material therefrom will help to build his resource bank. It is not essential, but it helps if he is a competent public speaker; certainly he will be asked frequently.

A weekly column for the disabled fills an existing gap in the media provision for the disabled. In no way does it overlap the work of the present national 'disabled' magazines, but it does draw strength and guidance from them. Regrettable as it may be, the majority of disabled people see none of this literature. Disabled newspaper readers are prompted to bring relevant matters to the notice of the caring professionals. Through reading the column, the general public, including the decision makers, are made aware of the problems and aspirations of the disabled. The national organisations have little influence in the town halls where many matters affecting the disabled are discussed. The gospel according to RADAR will reach more of the Phillistine decision makers through the pages of a provincial newspaper than through any other medium.

APPENDIX

Some of the subjects covered in the period January - June 1978

Facing Life in a Wheelchair

Communication without speech

Access

Be selfish - Help others

Spread Your Wings and take a Holiday

How poor sight can be brought to book

Give us better understanding

Crossroads

Sport for the Handicapped

REMAP

Parliamentary News

Motoring for the Disabled

Le Court Cheshire Home

Portsmouth A.L.A.C.

Access

Education

D.I.G.

Employment

Spare a thought for the caring relative

Employment Rehabilitation Centres

Access Week

Caravan Holiday

S.I.A.

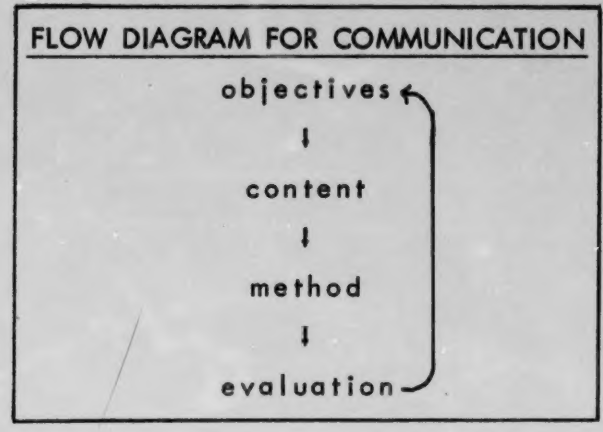
M.S.

Radio for the Disabled

PROBLEMS OF COMMUNICATION IN CHRONIC ILLNESS

Michael R. Bury

The very organization of this session indicates that we recognize we have problems, that communication in medicine and rehabilitation is not all that it could be. In order to diagnose the nature of these problems we need to start with a model for the process of communication. Essentially we are concerned with the transmission of a message from a source to a recipient, and we need to consider each of these in turn, the message, the method of transmission, the recipient, and the source.


FLOW DIAGRAM FOR COMMUNICATION

Let us start with the message. It is intended to accomplish something – in other words, it has a purpose or an objective. This influences its content and, in turn, how this is presented. Although quite a lot of studies of communication in medicine have been carried out, these have tended to emphasize variability in the patient's understanding and recall of information transmitted.

This has led to exploration of how information has been presented – the words used, the role of illustrative material, the value of written reinforcement, and so on. Most of this work has studied style or form – in other words, an evaluation of the method of transmission. But as the flow diagram above shows, the method is subordinate to the content, and it is about the factors relevant to content that I wish to comment. First, though, we must clarify what our objectives are.

Obviously the first objective of physician-patient communication is for the physician to become informed about the patient's problems. Only on this basis can the professional develop a satisfactory appraisal of the situation, and without this the responses are scarcely likely to be appropriate.

OBJECTIVES OF PHYSICIAN–PATIENT COMMUNICATION

1. inform physician about patient's problems
   (→ comprehensive professional assessment)
2. influence patient's response to illness
   - to allay anxiety
   - to enhance adaptation and coping
   - to encourage acceptance of professional advice

The other main objective is to influence how the patient responds to his illness experience. The professional is likely to have three main aims in mind as I have displayed above. It is the last one, the encouragement of acceptance of professiona advice, to which I should like to draw particular attention. When patients are er couraged to accept advice and to act on it, there are two important things to be borne in mind. First, an assumption is made that the advice is correct, and this often leads to a presumption that any right-minded individual would act on it – hence the use of the word compliance. However, this is too simple a view becau it neglects the second important thing, something that is especially relevant in chronic disease.

The patient is not a passive agent. The reality of the physician-patient interactic is in fact a process of negotiation. Advice is tailored to the individual patient as much as possible, and underlying this is a negotiation between what seems to the doctor to be desirable and feasible, and what the patient sees as relevant and is therefore likely to act on.

An important reason why negotiation may be unsuccessful is that communication is failing. This is where we turn to how the message needs to be relevant to both source and recipient. The difficulty is that there is a discordance between physicians' and patients' views. Physicians seek understanding in terms of disease phenc mena, because this is whence they gain their power to intervene.

DISCORDANCE IN COMMUNICATION

physician conceptualizes situation in terms of disease phenomena

patient reacts to his experiences :

- practically, in regard to how disabilities affect him
- symbolically, in relation to lay concepts of illness

But the patient is aware of how his bodily processes are disturbed, mainly through the disabilities these give rise to, and of how such sickness experiences are comprehended within his universe — in other words, the symbolic aspects of lay conceptions of illness and the cultural values attached to these experiences.

It should now be evident that too often what is communicated relates too closely to the physician's conceptualization of disease phenomena. If we are to improve communication our messages need to take more account of the recipient's terms of reference — to lay responses by individuals to the problems experienced in the course of an illness. What are these?

SIGNIFICANCE ATTACHED TO SYMPTOM EXPERIENCE

identity	- chronic pain and incapacity assault self image
biography	- uncertainty in outlook for future
explanation	- why me? and why now?
regimens	- prescribed routines are reassuring
legitimation	- acceptance by others important
stereotypes	- inappropriate expectations make situation worse

I have been documenting aspects of lay responses to illness in a study of rheumatoid arthritis in Manchester, and I would like to put forward some of the major components which emerged.

Identity

Functional limitations or activity restrictions as a result of an illness have profound effects on a person's self image. Bodily changes and the impact of persistent pain significantly alters self-perceptions. In a number of ways the individual becomes a different person and has to face the fact that there will never again be a return to the old "self". This forces the individual to seek an understanding of the nature of the processes that are taking place.

Biography

Alteration in self image, together with what the patient learns of his condition, serve to heighten a feeling of uncertainty about the future. In many ways the changes represent a deterioration that may be likened to premature ageing. So expectations for the future unfolding of life, in other words their biography, are threatened and have to undergo modification.

Explanation

By the same token, the reason why the disease has occurred at all is profoundly disturbing. The questions why me? why now? are constantly present. Suffering without an explanation is all the harder to bear. Patients search through their personal and social biographies, as well as their family trees, in attempts to locate events or factors which might help explain the occurrence. On occasion such re-examination is a persistent feature of the attempt to come to terms with the illness.

Regimens

The lack of explanation and the presence of uncertainty manifest themselves in practical ways as well. Actions to mitigate or reduce pain and stiffness in a condition like rheumatoid arthritis are by no means straightforward. There are problematic choices about the balance between rest and activity. The background disease state is variable, and advice changes as the nature of the manifestations alters. All of these difficulties are in sharp contrast to the more consistent and detailed programme that can be put forward say for ischaemic heart disease. Not only is this a higher status illness, but the precision of straightforward body maintenance regimens is more reassuring.

Legitimation

Illness and disability disrupt normal relationships, particularly in the family. The practical and emotional response to the experience of symptoms will be particularly affected by the degree of acceptance by others. Rheumatic symptoms are widespread in the community and therefore the ability of the individual to gain acceptance of his or her particular experiences is reduced. Difficulties arise in the early stages even in convincing a spouse that the illness is serious and that support is needed. Natural sympathy and tolerance in times of illness have limits, especially when a disabling condition is involved.

Stereotypes

Prevailing conceptions of disease and illness in our society can have profound effects on individual reactions. Where fatalistic conceptions exist insensitivity to difficulties may be present. Low expectations of treatment and outcome in rheumatic complaints exacerbate difficulties for the individual in maintaining normal relationships. As the illness develops, however, and its disabling consequences become visible and obvious, a tendency to over protection, for example, the encouragement of ceasing work among female patients, occurs.

This list is by no means exhaustive. This is hardly surprising as these aspects have been little studied, either by the medical profession or by sociologists. However, it does suggest that, if doctor-patient communication is to be improved, two things are needed :

i) further work to increase knowledge of lay comprehension of illness phenomena;

ii) attempts to promote greater understanding of the difficulties, particularly in the community, so that social relationships can become more sensitive.

DISABLEMENT INFORMATION AND ADVICE LINE (DIAL)

JOHN GRANT

ABSTRACT

This paper describes the setting up of a telephone information and advice service covering all aspects of disablement. It describes how that service, with the co-operation and encouragement of national disability organisations has, in turn, encouraged other local groups to form. It also sets out how these local groups are now getting together to form an association of disablement information and advice services and how this association has perceived the need for a central information source to service local groups.

RATIONALE

The Disablement Information and Advice line (DIAL) was conceived in Derbyshire early in 1976. Although it was the first local service to use the name DIAL it was by no means the first information service for the disabled. A scheme had been set up some five years earlier in Newcastle and the Manchester Telephone **advice** bureau (TAB) had just started operation and was being run by the late Brian Torr.

Both Ken Davis, who was to become DIAL's chairman, and I had been independently operating an informal service to our friends and acquaintances. Ken's knowledge was founded on 14 years hard experience of being severely disabled having suffered a C6 lesion of the spinal chord in a diving accident.

My own experience is based on growing up with a paraplegic father, seven years designing for the disabled at Mary Marlborough Lodge and; latterly, four years as principal of a residential and day centre for the physically handicapped. Our own experiences had proved that the availability of information, in a concise and cogitable form was such that it was almost impossible to retrieve unless one had the time, money and articulation to chase from department to department or to spend endless hours on the telephone.

We felt that there was a need to provide, not only referral information, but also a direct service with back-up in the form of written information and advocacy.

PRINCIPLES ON WHICH DIAL WAS FOUNDED

It was felt, at a very early stage, that all the telephone operators should have a direct personal experience of disability. It was, however, made very clear that they should be selected to suit the needs of the service. It would be all too easy to set up a service to satisfy the needs of the operators. The aims of the service are to give direct information wherever possible. It would not, for instance, be sufficient to say to an enquirer "Contact the Department of Health and Social Security (D.H.S.S.)"or "Contact your social worker" without first feeling assured that he or she could successfully follow the enquiry through. But it is equally necessary not to rob an enquirer of the capacity to

help himself. Giving information to help people, better, to help themselves is pre-requisite.

Considerable discussion was held about whether DIAL should act as a pressure group. It was generally felt that the provision of information should be its central role. Giving information can, per se, lead to pressure for change. It was considered that the recipient of information could then use it as he felt most appropriate.

DIAL, however, is not purely a passive group. There were envisaged active roles in both propagating and collecting information and that there would also be a more direct form of pressure exercised by DIAL when acting in the role of advocate.

SCOPE OF SERVICE

The geographical scope should, ideally be limited to a local telephone call area. Enquirers wanting to be informed if there is any other benefit to which they are entitled, because they find it difficult to manage on their present income, should not need to keep increasing their call charges or spend a great deal of money in a pay phone to get the information they require.

The scope should also provide for personal callers who feel that they need to talk over their problem at some length. Accessibility in terms of location and in physical terms is, therefore important.

As far as DIAL was concerned it was agreed that it should service disabled people, principally within Derbyshire, from a reasonably central and accessible point.

Accordingly we directed our advertising within the county, saturating all the Social Services offices, General Practitioners' surgeries, hospitals and disabled clubs with posters and information leaflets.

Initially we also enjoyed considerable coverage from the local and specialist press.

Soon after setting up the service, in January 1977, we realised that the effort of collecting and collating information would be largely wasted unless we had some way of actively propagating that information to those people in most need.

The first, and most effective method that we employed was to contact the local radio station, Radio Derby, and to negotiate a five minute spot each week to keep people informed of new developments in the sphere of disablement and to clarify some of the issues. "DIAL News", as the programme has become known, is now a regular Monday feature and, judging from the feedback, a valuable method of disseminating information. Our volume of enquiries doubled when "DIAL News" was introduced.

Another active method of increasing the scope of the service is through the issue of occasional bulletins (e.g.) The change in law affecting the declaration of Mobility Allowance on income tax returns.

It was thought, at the beginning, that the scope should not be limited to preclude any inquirer. We have found it as effective to direct information to professionals working within the sphere of disablement as to direct information at disabled people. About 20% of the calls received by DIAL Derbyshire have been from professional sources, from architects, social worker, nurses, etc. We have also received enquiries from such sources as Consultants in physical medicine and the Inland Revenue.

Accordingly the advertising literature makes the point clear that it is open for anybody to avail themselves of DIAL services.

SETTING UP THE SERVICE

The principle hurdle to be overcome in setting up a DIAL service is, of course, one of finance. The source of funding can put the service on a tightrope: he who pays the piper may well wish to call the tune. The service cannot afford to be seen to have an allegiance biased towards the benefactor. That would completely destroy consumer confidence.

In Derbyshire the majority of our funds have been forthcoming from the Local Authority in the form of a direct grant from the County Council's self-help fund. The administration of this money is left completely in the hands of DIAL.

DIAL does not, however regard itself as being under any obligation to the authority. If the cudgels need to be taken up on behalf of an enquirer, and the adversary happens to be the Local Authority then this is done without compunction.

Derbyshire County Council also provide DIAL (albeit under some pressure) with premises. The office is situated within a residential and day centre for the physically handicapped in mid-Derbyshire. The advantages of this siting are (1) thatit is readily accessible to the most severely disabled; (2) it has adjacent parking facilities; (3) a range of purpose built toilet facilities are to hand; (4) attendants are available if required.

This further link with the County Council could be seen as an additional tie and potential disadvantage but DIAL, as a voluntary body, is properly constituted as an independent and autonomous association. It sees it as being essential to create the conditions for co-operation and co-partnership with statutory vodies.

So DIAL now had funds and an office from which to work.

As part of our programme to gather information prior to opening we wrote to a large number of voluntary and statutory agencies asking them to let us have a brief abstract of their activities, the name of a local contact, if any existed and to list their publications and periodicals together with the appropriate price or subscription. About 90% of those contacted replied. Some of these are still sending us, free of charge, their newsletter and/or other information.

Other basic information sources obtained included such well known publications as "Equipment for the Disabled"; "Disability Rights Handbook" and "Holidays for the Disabled", along with subscriptions to R.A.D.A.R's bulletin and the Disabled Living Foundation's information service.

Because of the need for speedy recall of highly specific information a flexible and effective indexing system was developed, involving a main subject index subdivided, in the light of experience, into more detailed components.

In developing the filing system we thought it necessary to forge a link with Derbyshire County Library. This link has provided, for DIAL on extended loan, many of the books which go to make up our small library. If the books are required by a borrower they are recalled for that purpose and then returned to us. DIAL advises the library service of their book needs and it is a measure of their willingness to co-operate in that, when funds permit they purchase for us some of the more important publications.

Going back to our perceived need of a direct service with back-up we had to obtain both a typewriter and a photocopier. The typewriter needed to be electric as the typists would almost always be disabled. We are fortunate enough to be able to buy one for £40.00 through the Spastic society/IBM scheme.

Our first photocopier was a discard from the local Social Services office and it was capable of producing only single copies which then had to be dried. Later a grant of £1,000, towards the administration of DIAL, from the Carnegie United Kingdom Trust enabled us to buy a modern plain paper copier, an article of equipment which has since become essential to our mode of operation (i.e) to actively disseminate information to those who need it rather than to passively wait for them to contact us.

Clearly the telephone was an important piece of equipment and was carefully chosen to facilitate operation by disabled people. The type eventually chosen was a loudspeaker telephone.

Obviously I have not mentioned all the sources of information that we approached, or the methods of storage and the general design of the office, etc. To do so would make tedious a procedure which is best dealt with by individuals having regard for their own need in a particular situation.

SELECTION AND TRAINING OF OPERATIVES

An important point in the selection of operatives was, as I have already premised, that they should be the right people for the service and not to make the service match up to their needs. At a recent seminar this very point became the topic of fierce discussion. It was generally agreed that an operator would need to have direct personal experience of disability but this need not necessarily mean that he/she must be disabled. It was felt at the seminar that "the wrong person could cause a lot of damage and that each operator must have the ability to give concise and accurate information and, if necessary to lend a sympathetic ear".

How such people are found presents yet another problem. Often you will find someone, in an area, already informally giving advice and help; whilst some schemes advertised in the local press for volunteers, and then took up references before selection.

In Derbyshire we have felt that induction training is the best way to acquaint new operators with procedure, both in the retrieval of information and in acquiring a "telephone manner". A set of guidelines for the use of operators has been drawn up. It must be pointed out and accepted however, that efforts to attain uniformity of service will always differ according to the individual approach of different operators. Other local groups, throughout the country have employed alternative training schemes. Some, for instance, run short evening courses on welfare rights whilst others rely entirely on their personal experiences.

COLLABORATION WITH LOCAL ORGANISATIONS

It is useful and comforting to feel that one is not entirely alone if advice is bordering on the terms of reference of DIAL groups. The back-up of local organisations is often available if required. Indeed some groups have made it their business to set up a programme of involvement with local voluntary groups as part of the process of training. An obvious link exists between DIAL groups and CABx and early contact is necessary to operate in a complementary and harmonious way.

The relationship with the Social Services can be something of an enigma. One minute you will be soliciting their help on behalf of an enquirer and the next minute you may well be questioning seemingly bureaucratic or pedantic procedures which delay or obstruct individuals exercising their rights. This tension is an inevitable effect of the system and has, unfortunately to be lived with.

Local groups should systematically endeavour to catalogue local voluntary bodies which will then form an essential part of their own information system.

EARLY EXPERIENCES

In the early days of running our service its value quickly became apparent. Calls on the service were running at about 100 per month, which is a vast, previously untapped area of need. We considered that what we had found in Derbyshire should also be apparent generally. The Newcastle service confirmed this view when we were able to compare our statistics, on enquiries received, with theirs. Additionally some of the national organisations had said that they were beginning to be inundated with enquiries from all over the country and that they would welcome a growth in local information services. Indeed this growth was occuring as we received more and more calls from groups wishing to set up services similar to DIAL.

It had taken us nine months to get off the ground and we felt that we could now usefully pass on the fruits of our own experiences to others.

SEMINAR

With all this in mind a seminar was held in Derbyshire on 5th October 1977 when more than 70 delegates from all parts of the British Isles attended.

In referring to the need for a seminar the Chairman said that a critical and objective look at specialist local information services for the disabled was needed at that point in time.

After a day of discussion the seminar called for another meeting to consider the need for a national association of local information groups and the feasibility of setting up a central information source to service them. The preliminary investigations were mandated to DIAL Derbyshire and Ken Davis was asked to act as co-ordinator.

It was also pointed out at the seminar that the D.H.S.S. were involved, through the Disability Alliance, with pilot schemes similar to DIAL which had been set up to assess the need and evaluate the effectiveness of such services as a prelude to possible national development.

FUTURE OF SERVICE

In answer to the call made by the seminar subsequent meetings were hosted by DIAL Derbyshire which culminated in (a) the formation of a steering committee to set up the National Association of Disablement Information and Advice Services (N.A.D.I.A.S) and (b) the formation of a development committee, consisting of DIAL delegates and representatives of national disability organisations, to explore ways in which a central information service, known as "DIAL I$_n$formation" could function.

Only time can tell what will evolve from these committees. There is no doubt that the need for information exists. The question about whose responsibility it is to provide that information remains. Beveridge in 1948 said that there should be "In every Social Security office an advice bureau to which every person in doubt or difficulty can be referred and which will be able to tell him, not only about the official provision but also about all the other organs - official, semi-official and voluntary, central or local - which might be able to help him in his difficulty".

You may want to question whether such an information service based in the D.H.S.S. offices would, in fact (a)give unbiased information or (b) present such a stigma in mere attendance as to be an unacceptable source of advice for many people.

Ann Howard in her recent book "Welfare Rights, the Local Authorities Role" put the onus fairly and squarely on to the shoulders of the Local Authority. Alf Morris and Jack Ashley share this view and they are, at this moment, seeking to amend Section one of the Chronically Sick and Disabled Persons Act in order to place on the Local Authority a duty to provide information services for the physically handicapped.

Another possibility is to develop a fresh version of Britains library service. There is no doubt that our library service is the envy of the world and it has information sources second to none; it exists at a point in time where technological development has pushed us to the brink of public accessibility of information which, a few years ago, would have seemed like science fiction.

This vision would include an acceptance by the library network of information needs - and their corollaries, advice and help - beyond that which they presently embrace.

Our library system is there, its expertise is available now, and its potential for development is limited, as much by failure to appreciate the desparate needs of people for information of all kinds, as by limited resources. Whatever the future holds, the present is full of hope. DIAL groups continue to form. There were, at the time of writing 21 such groups in existance, all dedicated to the greater aim of ensuring that the "fourth right of citizenship" the right of information and advice is available on a free, confidential and an impartial basis to anyone concerned with the problem of disability.

ACKNOWLEDGEMENT

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EUROPEAN CONFERENCE OF REHABILITATION INTERNATIONAL

'Disability in the Family'

18th - 21st September 1978

BREAKING BARRIERS TO THE EMPLOYMENT OF THE DISABLED

Hilary Schlesinger

BREAKING BARRIERS TO THE EMPLOYMENT OF THE DISABLED

Hilary Schlesinger

Legal provisions and policies for furthering employment opportunities for the disabled exist in most countries, but in practise there are still many barriers which prevent them from achieving a satisfactory working life. More people could be found suitable employment if greater use were made of modern technology, aids and good job design for developing skills and new job opportunities.

Isolated solutions developed to enable individuals to work effectively and with satisfaction have not been pooled or publicised for general application.

A resource which would collect, evaluate and disseminate information on occupational aids and advise on their application, would help to break many existing barriers to the employment of disabled people.

This paper is about a project for developing a resource of this type as a means to improving their employment prospects and shows how it could benefit the disabled, employers and all those concerned with resettlement.

INTRODUCTION

Over the past ten years the major theme for the disabled throughout the world has been their full integration into the community. Previously the emphasis was largely on providing services which made it possible for them to carry out activities common to all, but in a special or segregated environment.

Laws and policies introduced during the past ten years in many countries have opened the way for disabled people to live, be educated and to work alongside people who are not disabled. The international symbol of access for the disabled, now familiar to the public at large, is a constant reminder of the responsibility held by all to help them to lead a normal life in the community. This responsibility extends to those with severe disablement who until now have had very limited opportunities.

Integration is a process which is not achieved merely by discovering a material solution to a problem. It requires positive attitudes, understanding and insight on the part of everyone in the community, including the disabled person. In this sense, it is not physical integration at all costs that is the ideal, but identification with the rights and needs of the disabled person and the provision of maximum opportunities for the development of their potential and greater freedom to enjoy the life of their able-bodied counterparts.(1)

Hilary Schlesinger, MBAOT, Research Officer, The Spastics Society, London.

The process can be summed up in five areas:

- Awareness of the problem
- Education - through information and experience
- Declaration of policy
- Legal measures
- Action

INTEGRATION OF THE DISABLED IN EMPLOYMENT

In the field of employment it is probably true to say that policy and legislative measures are in advance of action. Laws and policies exist in nearly all European countries which enforce employment of the disabled in private and public companies.(2) An increasing number of countries make provisions for adaptation of the work place and aids to facilitate the employment of the disabled, including the improvement of access and means for mobility.(3) On the part of the disabled and organisations representing them, there is an increasing concern for bringing in practical measures which will enable severely handicapped people to make the maximum use of their abilities, to achieve job satisfaction and to participate as fully as possible in normal patterns of work.

In spite of this, barriers still exist for their integration into employment. There is often a disparity between available jobs and the disabled people seeking them. The working and medical worlds have had little contact and therefore have little insight into each others problems. As a result employers have not, on the whole, had the experience of employing the more severely handicapped, and rehabilitation specialists have lacked realistic aims in preparing the disabled for employment. Little use has been made of modern technology for developing skills and new job opportunities. Problems of accessibility and means of getting to work still need to be solved.

NEED FOR INFORMATION ON OCCUPATIONAL AIDS AND THEIR APPLICATION TO THE EMPLOYMENT OF THE DISABLED

In recent years there have been many advances in the development of aids and equipment for severely handicapped people. On the whole, these new developments have concentrated more on enabling them to achieve a degree of independence in their home and social environment than in employment. Although there are several organisations in Europe and U.S.A. which are concerned with developing technical aids for the employment of the disabled, their work is not widely publicised. Apart from certain developments for the blind and the deaf, most solutions that have been developed and applied in the employment field are limited to the individual and are not generally known. No comprehensive record has been made of these solutions, either nationally or internationally, even though they may help others with similar problems.

This lack of information and experience is likely to have influenced recent findings on employers'attitudes in this country.

In Great Britain, the rate of unemployment of registered disabled people, capable of being employed, is approximately 2½ times that of the population as a whole.(4) In order to improve this situation and to help break the existing barriers, in 1977 the Manpower Services Commission (MSC), which has responsibility for employment and training services for disabled people, launched 'Positive Policies'(5) - a guide to employing the disabled. This aims at encouraging employers to adopt policies which cover all aspects of the problem. In March 1978, the MSC carried out a study of employers' attitudes to 'Positive Policies' and found significantly different levels of acceptance of the six points it contains. The results were as follows:

1.	consideration of disabled people for all vacancies	88%	acceptance
2.	retention of newly disabled employees	92%	acceptance
3.	equality of opportunity at work	92%	acceptance
4.	modification of equipment or jobs if needed	46%	acceptance
5.	adaptation of premises where needed	54%	acceptance
6.	co-operation with the employment officer (DRO)	79%	acceptance

These findings are based on reports of visits made to over 4,000 employers(6) and indicate that, whilst they are on the whole responsive to employing disabled people in general, there is an obvious resistance to the employment of people for whom modifications need to be considered. If the effectiveness of practical aids, good job design and methods were more widely appreciated by employers, these policy points are likely to be as acceptable as the others. This appreciation would best be achieved by widespread dissemination of information and demonstration.

The number of aids issued in the U.K. to disabled people working in open employment is increasing each year. Firms such as Gestetner are developing ways in which their machinery can be adapted to accommodate people with a wide range of disabilities. However, it is still important for information about individual solutions to be made more widely available for the benefit of others with similar problems.

A resource which would collect, evaluate and disseminate information on occupational aids and advise on their application, would help to break many of the existing barriers to the employment of disabled people.

PROJECT FOR THE DEVELOPMENT OF A TECHNICAL INFORMATION AND ADVISORY SERVICE ON OCCUPATIONAL AIDS FOR THE DISABLED

The main purpose of this paper is to outline a project for developing a service of this type which resulted from findings of two recent studies of disabled people in employment.(7) These were carried out in the U.K. by the research department of The Spastics Society and the Production Engineering Research Association (PERA). Both studies recognised the need for a technical information and advisory service on occupational aids and their application to the employment of the disabled, as a means of implementing recommendations made for improving the productive ability and job satisfaction of disabled workers.

It was felt that a venture of this kind required close liaison between employers, trade unions and rehabilitation personnel. Also, for an effective service which would be recognised and used by industry as well as by rehabilitation personnel, it was considered that ideally the service should be operated in an organisation which maintains close links with industry.

As Mr Groves of PERA indicated in his talk at the conference, his organisation has undertaken projects which are directly relevant to the proposal. PERA is an industrial research body with international membership which provides information, consultancy and training services to all kinds of industry and commerce. It also carries out practical development work in the field of industrial processes. It offers a translation and publications service, operates the largest production engineering library in Europe and is in a unique position both in receiving information from industry and transferring technology to industry on a day to day basis.

Through their membership, The Spastics Society approached PERA in January 1978 to consider developing a specialised information and advisory service on aids to the employment of the disabled, as an extention of the normal service they provide, thereby carrying the concept of 'integration' into the field of information.

A number of Government, voluntary and international organisations concerned with the resettlement of the disabled were contacted in order to ascertain whether a service of this type already existed and, if not, whether the idea was thought to be useful.

The idea generally received support and apparently a similar service did not exist. As a result PERA agreed to carry out a feasibility study for setting up a computer based service of occupational aids and their application to the employment of disabled people, which would meet the needs in practical terms of the disabled, employers, trade unions and all those concerned with resettlement. It is being carried out in close collaboration with the Research Department of The Spastics Society and the Resettlement Section of the Manpower Services Commission's Employment Service Division, as well as consultants from other organisations and Government Departments involved in the rehabilitation of the disabled.

The study aims to investigate the optimum system for collecting, evaluating and disseminating the information and for enabling rapid retrieval of data relevant to the solution of problems encountered in the employment of the disabled. Guidelines will also be established for the provision of a service which, working in conjunction with the data bank, would promote the implementation of known aids and useful technology advances and contribute to the development of new aids.

Questions will have to be answered such as how the service will operate on a long term basis in terms of location, personnel, funding and users, as well as who would assess the needs of the disabled and in what form the information should be distributed.

For the purpose of this service, the term 'aid' is used in the widest sense. It relates not only to the use of devices developed specifically for disabled people, but also to the use of certain power assisted equipment, which is commercially available and already widely used in industry and commerce; to the use of job simplification through job design, method study and ergonomics; to the application of modern technology.

WAYS IN WHICH THE SERVICE WILL BREAK BARRIERS TO EMPLOYMENT

There are many benefits which should result from a service of this kind. They fall into two categories, immediate and future, and can be summarised as follows:

Immediate Benefits

The provision to employers and resettlement workers with information and practical guidance on ways of using the potential of disabled people in specific jobs will result in;

1. A greater range of employment opportunities at all levels,

2. An increase in the possibilities for those with more severe disablement to compete with and operate alongside the non-disabled,

3. The development of positive attitudes amongst employers towards breaking down existing barriers, in the environment as well as in the job,

4. It will lead to an improvement in the prospects of all disabled people to realise their full work potential. In some cases this would mean those in sheltered workshops moving to open employment; in others, those considered unemployable achieving sheltered employment; and greater job satisfaction for those who remain in a sheltered environment.

Future Benefits

The analysis and classification of available information will result in;

5. The early identification of areas needing further 'aids development',

6. An indication of further applications of existing aids. e.g. The application of aids for communication and purposes other than work in the field of employment,

7. The direction of research and financial resources to those areas giving the greatest benefit to the greatest number of people,

8. Aids developed for carrying out a task in the field of employment will inevitably find application in performing similar tasks outside employment.

Probable Future Developments

An effective information service could lead to the establishment of a matching system for determining the most suitable types of job for a particular disabled person, and indicate areas of disparity needing aid development.

It should also result in the development of improved techniques for assessing the disabled person's capabilities and needs in employment.

A very significant outcome of this scheme would be the establishment of a close working liaison between employers, trade union representatives and rehabilitation specialists.

HELP NEEDED

At this stage we are interested in collecting any information on existing solutions supported by case studies, both in open and sheltered employment, and we ask anyone who knows of an example of a handicapped person enabled to work through some special aid or method to contact us. Developments and solutions applied in other countries are of special interest to us.

At a time when we are all seeking to further opportunities which will contribute towards fuller integration of disabled people in the community, we feel that one way of achieving this, in the field of employment, is by bringing together the wealth of expertise and information so that it can be used for the benefit of everyone concerned throughout the world.

Please send any information to: Miss Hilary Schlesinger,
Research Officer,
The Spastics Society,
12 Park Cresent,
London W1N 4EQ.

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THE DIFFICULTIES OF INFORMATION PROVISION FOR THE DISABLED AND THEIR FAMILIES

Sheila Cooper and Julie Spicer

ABSTRACT

This paper describes the complexity of current information provision for disabled people and their families, and the barriers that confront them in obtaining vital information. It outlines the problems faced by those working in the field of disability in providing their clients with up-to-date information. The emergence of local information services as a possible solution to the difficulties of information provision is described along with the work of the Institute for Consumer Ergonomics.

INTRODUCTION

> "People will not be able to get their due as citizens of present day society unless they have continuous access to the information which will guide them through it, and, where necessary, the advice to help them translate that information into effective action". [National Consumer Council 1977]

Disability creates a need for information on specific services, facilities and general aspects of daily living in order to prevent disability causing great handicap to the individual and his family. The family must learn how to cope with the various situations that will arise, they need to learn new skills, to adapt their way of thinking and be prepared to plan activities which a family without a disabled member may not think about. The family with a disabled member needs to know about the existence of a multiplicity of tools, aids, places, facilities, services and benefits that are available. However, there is very rarely one general source of information, advice and help to enable a family to cope with disability. Vital information is often discovered purely by chance and the search for information appears to be carried out in a haphazard fashion because people do not know who to approach.

THE INFORMATION PROBLEM

Essential information and advice on various rights, services and facilities for disabled people may need to be sought from a variety of places.

1. Information on facilities to assist in the home must be sought from Social Services departments, Housing and Planning departments of the local District or Borough Council, the Gas and Electricity boards, the Department of Health and Social Security, the Inland Revenue and voluntary organisations.
2. Information on mobility aids and forms of transport must be sought from Hospital departments, Artificial Limb and Appliance centres, (or limb fitting centres) Social Security offices, local District or Borough Councils, British Rail, airlines and airports, and voluntary organisations.

Institute for Consumer Ergonomics,
University of Technology,
Loughborough,
Leicestershire.

3. Information on employment services must be sought from the Disablement Resettlement service at local Jobcentres or Employment offices which form part of the Department.
4. Information on services for handicapped children must be sought from the Health Services, Social Services, the local Education Authority, Child and Family Guidance centres and voluntary organisations.
5. Information on benefits, pensions and allowances must be sought from local Social Security offices.
6. Information on a variety of other facilities which may be needed by disabled people such as holidays, sport, recreation and social facilities, must be sought from local voluntary organisations or sometimes even national voluntary organisations.

This merely represents a selection of information which disabled people and their families may need. And yet this number of agencies alone creates a bewildering complexity of information sources. This complex pattern is further aggravated by a lack of co-ordination between the various bodies often due to their differing policies on information provision as well as the more obvious restraints of time and finance.

BARRIERS TO INFORMATION

Disabled people face barriers of several different kinds in trying to reach information. Firstly the purely physical barriers of access. Secondly, the barriers created by a lack of knowledge of the relevant body to approach, and the correct procedure to use. Thirdly, the barriers created by the form in which the information is often presented.

Information is often presented in such a way that it is obscure and confusing rather than enlightening. Many leaflets and forms take for granted certain levels of literacy and numeracy and many actually use archaic language and tortuous syntax. Leaflets produced by the DHSS to publicise benefits often put too great an emphasis on disqualifying factors so that people do not realise they are entitled to claim.
A lack of knowledge of the system creates a barrier. We have illustrated how difficult it is for people to know which of the large number of organisations to approach for information. Then, once the information source has been located, a contact must be made, the correct questions asked, the relevant details given and the correct procedures followed.

Section 1 of the Chronically Sick and Disabled Persons Act of 1970 obliges local authorities to publicise their services for disabled people. However, this legislation appears to have done nothing to provide equality of access to information. Some Social Services departments do very little to publicise their facilities, and many disabled people do not take advantage of the services they offer because they are not aware of what is available. Is the reason for this reluctance to make services more widely known an attempt to restrict demand? It would appear that this is the case.

INFORMATION TO THE FIELD

Important channels through which the family coping with disability are likely to receive information are the professional field workers such as occupational therapists, health visitors and social workers, and the voluntary organisations for disabled. Often the family will look to these groups for information and expect to be given all the relevant details that they need to cope with their handicap.

Field workers are expected to have information both about the services which they provide and also other more general services and facilities for disabled. One way to keep abreast with current information is through the professional journals but limitations arise because the amount of work and information produced cannot be covered by the journals, the time which field workers can spend scanning them is limited, and the cost of holding serial literature is high. The field worker is a point of contact between the family coping with disability and the community as a whole. The exchange of information between field-work staff representing different agencies is important. Greater liaison between all the professionals concerned with the disabled and their families could do much to improve information flow. Problems in achieving this liaison arise through agencies having different terms of reference in relation to their clients' needs, and limitations of time. C. J. Melotte, in researching into the ways in which social workers receive information [Melotte, 1977] found that 10% of those he interviewed could think of none of the six most common benefits for disabled people. (Attendance, Mobility, and Invalid Care Allowances, Supplementary and Invalidity Benefits and Non-contributory Invalidity Pension).

Voluntary organisations for disabled must obtain their information in whatever ways they can, again according to restraints of finance, staffing and knowledge of sources. Voluntary organisations vary in the amount and type of information which they have available. Some are concerned with specific handicaps, some with specific facilities or services, while others may act as referral points to other bodies.

Consistent, up-to-date information designed for those working with the disabled and their families is obviously greatly needed. Unfortunately, it would appear that there is an ever increasing price placed on information; whether directly in cash terms or time spent. Perhaps a reappraisal of the resources needed to adequately supply essential information to all those working with disabled should be made.

ATTEMPTED SOLUTIONS

In order to overcome some of the problems caused by this lack of information and inequality of access, self-help groups are now emerging with the prime objective of providing information services for disabled people. The fact that these new groups, specifically concerned with giving information to disabled people, are being set up alongside the already existing local and national voluntary organisations illustrates the need for comprehensive information services. Although the established national and local organisations for disabled people provide a good service, it is often in certain fields only, such as specific handicaps, or certain types of information. The new information services are trying to be comprehensive in providing accurate information on all services and facilities which disabled people may need to know about.

The information given is usually of a fairly local nature tending to refer to one geographical area such as a county or borough boundary. Such an approach overcomes many of the variations in procedures and provision of services which occur through the county, because many services are provided at the discretion of local authorities on varying budgets. These variations can create problems for the disabled person trying to get information. Although a national organisation can outline the general provision made by Social Services departments, this may not be entirely accurate in a particular area at any one time; and disabled people and their families can also face problems in getting information from local organisations because of their number and the variety of their provision.

A local information service , however, can give up-to-date and accurate information on the provision of services and eligibility for them in any one area. Local information services for disabled people are provided in several different forms. First, there are access guides to many towns, giving details of physical accessibility. Second, there are handbooks or directories of local services and facilities for disabled. Third there are telephone information services for the disabled. Of the local handbooks some are mainly for families with handicapped children; some briefly outline available services for disabled; others include more detail. [Guide for Handicapped children and their Families, Haringey, 1976; Help for Disabled People in Westminster, 1977; Help, Advice and Information in Rotherham, 1978; AID in Leicestershire 1978] Handbooks may be useful to newly disabled people and to the professionals working with them in that a range of information is immediately at hand. Disadvantages arise, however, through information being badly presented and difficult to find; publications soon becoming out of date; and information still being restricted to those who can read and will use a reference book.

Of the telephone services for disabled there are now about 19 spread throughout Britain. Some now go under the name of DIAL -Disablement Information and Advice line. They tend to be run on a voluntary basis usually by disabled volunteers. Some receive help and support from county councils through Social Services departments or the library services; others are backed by voluntary organisations. These services have been set up independently to serve pressing local needs, and their numbers are still increasing. A reflection of their importance is shown in the recent formation of a national association of DIAL-type groups. Limitations to telephone information services arise through financial constraints and the quantity and quality of information stored and given out, which may vary according to the number of people providing the service and the facilities available to them.

Despite limitations local information services are providing a vital source for disabled people and their families seeking information. Should they not be more widespread enabling more people to have access to information? Should not more support be given to establish such services and keep them running efficiently? One question remains and that is: should these local information services for disabled people continue to compensate for the lack of DHSS and local authority information, and will the latter therefore be deterred from increasing and improving their services? Should we rely on voluntary organisations to supplement or replace bad government information provision, or should we pressurise the DHSS and local authorities into publicising their services more fully?

WORK AT THE INSTITUTE FOR CONSUMER ERGONOMICS

Valuable information arising from research projects could be used to greater benefit if disseminated more effectively. Much research never reaches those who are generally involved in the area, but is reserved for the academic press, where they are presented in the form of research papers and where the exchange and flow of information is kept within a narrow field.

The Institute for Consumer Ergonomics has produced a handbook of information and advice for disabled people in Leicestershire - Aid in Leicestershire. This project was carried out at the suggestion of the Standing Conference of Voluntary Organisations for the Physically Handicapped in Leicestershire, and the work in collecting and collating the information was financed by the Manpower Services Commission under the Job Creation Programme. AID in Leicestershire includes details of both the statutory and voluntary bodies concerned with providing for disabled in the county, showing which provides what, where they are, who is eligible and how to apply. There are chapters on Social Services Department Provision, Benefits and Allowances, Health Services, Education, including Further Education, Employment, Housing, Heating, Holidays, Mobility and Transport, Children, Blind, Deaf, Sport and Recreation, Local and National Voluntary Organisations.

It was originally thought that the handbook would be aimed at those working with disabled people but it was soon realised that it was equally as important, if not more so, for disabled people themselves to have the information. Therefore, further research is being carried out to investigate other appropriate ways to disseminate the information to the public. This could take the form of leaflets, posters, the use of media including local papers, radio and television and resource packs. The Institute is also currently completing a four year research programme evaluating home aids for disabled people, sponsored by the Department of Health and Social Security, and is now investigating ways in which the results of this project can be made available to benefit all those involved in the area of aids and equipment for the disabled. This will include publications in wide circulation journals, and the use of various other media.

The Institute for Consumer Ergonomics is one of the various organisations that have attempted to provide some answers to the problem.

CONCLUSIONS

In the light of the difficulties of information provision outlined in this paper certain points for consideration arise.

1. More thought and research is needed into effective ways of generating and disseminating information to disabled people and those who work with them.
2. A greater number of comprehensive local information services need to be established using various forms of communication.

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INFORMATION SERVICES OF REHABILITATION INTERNATIONAL

Barbara Duncan*

ABSTRACT

The Rehabilitation International Information Services, providing material regularly to organizations and individuals in more than 100 countries, are described. Currently, two central depots exist: one in Heidelberg, functioning in English, French and German, and the second in Mexico, functioning in Spanish, serving Latin America. Others are anticipated. Rehabilitation International directs and coordinates these activities to help provide the best available information to those who need it.

The Rehabilitation International Information Service is comprised of equal parts of paper, research, selectivity and good will. The Service rests on the following assumptions or premises:

1) The basic components of the discipline of rehabilitation of people with physical and/or mental disabilities are the medical, vocational, educational and social aspects of the process and the accompanying supportive technical aids and prosthetic/orthotic devices.

2) There are mountains and floods of publications concerning rehabilitation published each year by government agencies, organizations and individuals in many different languages.

3) There is an increasing interest in rehabilitation throughout the world. The interest in internationally gathered information -- what other countries are doing to solve a common problem -- is also rising.

4) There should be central depots of this material, of these publications, which could organize, systematize, evaluate and circulate this information.

5) Rehabilitation International, with its 102 member organizations in 62 countries, international member organizations and thousands of working contacts throughout the world, is in a unique position to carry out these objectives.

With these premises in mind, Rehabilitation International began some 25 years ago to create a mechanism for carrying out these objectives. In 1973, a central depot was established for collection, analysis and circulation of information in French, English and German. The Center is located in Heidelberg, Federal Republic of Germany, through the generous assistance of Stiftung Rehabilitation Heidelberg, a major vocational and research facility. The functions of this aspect of the Rehabilitation International Information Services are:

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* Director of Information, Rehabilitation International

1) Paper: Currently, more than 500 periodicals in the rehabilitation field are received by the Heidelberg facility. The collection is augmented by congress and conference proceedings, technical reports from agencies and organizations, books and countless pamphlets and folders.

2) Research: Applying the first two definitions of "research" by Webster's Seventh New Collegiate Dictionary -- "careful or diligent search, studious inquiry or examination" -- the Heidelberg staff read and organize the material for the following purposes:

(A) The compilation of international bibliographies on subjects of current international concern. Approximately three of these are published a year.

(B) The compilation of a list of acquisitions, published about every two months, carrying full information on references considered to be of use to the international rehabilitation community.

(C) To be able to respond to inquiries concerning a particular subject or country.

3) Selectivity: Organizing this sea (or flood or mountain!) of material is an arduous task, but selecting what is particularly valable is equally difficult and requires careful analysis of the publications. The staff at the Rehabilitation International Secretariat in New York assumes the final responsibility for selecting:

(A) Material for the quarterly mailings of publications to members of the Rehabilitation International Information Service and to Rehabilitation International member organizations and officers.

(B) References for international bibliographies previously mentioned.

The last of the four ingredients and, perhaps, the factor which makes it all work is
4) Good will: The good will of many organizations and individuals who contribute their publications to this network without charge so that awareness grows of work completed and projects underway; the goodwill of the Stiftung Rehabilitation Heidelberg, which carries out a major part of the work of the Service for a nominal fee; and the good will of other international and national information services on particular aspects of disability, which have formed cooperating channels with Rehabilitation International. These examples of good will are concrete signposts of an international movement towards increased cooperation in the field of rehabilitation.

OTHER REHABILITATION INTERNATIONAL INFORMATION SERVICES

Gradually and with very limited resources, Rehabilitation International is also establishing other information service centers. In 1975, SIDIR, a Spanish language Information Service on Rehabilitation, was established in Mexico City with the assistance of the Permanent Inter-American Committee on Social Security. SIDIR publishes a newsletter and responds to requests for information in Spanish from Latin America. An Arabic language Rehabilitation Information Service is being considered and interest has been expressed in this development.

In summary, Rehabilitation International is aware of the need to continually expand and upgrade its Information Services and welcomes any suggestions from interested individuals. For further details, contact the Rehabilitation International Secretariat, 432 Park Avenue South, New York, N.Y. 10016, U.S.A.

Periodicals of Rehabilitation International

The International Rehabilitation Review, quarterly, providing news, brief articles, notices of international conferences and book reviews concerning rehabilitation throughout the world. Available for US$10 a year.

The International Journal of Rehabilitation Research, quarterly, providing original articles on rehabilitation research in English, French or German with summaries in the other two languages, research news, rehabilitation news, an extensive bibliography of recent research articles and publications and book reviews. Available for US$19 or DM36 a year from G. Schindele Verlag, Rheinstrasse 5, D-7512 Rheinstetten 3, Federal Republic of Germany.

INDEPENDENT LIVING PROGRAMS

David R. Williamson*

ABSTRACT

The purpose of this paper is to describe the status of independent living alternatives for the disabled in the United States. In the last 15 years, the disabled have joined with the common goal of seeking an independent life for themselves and others. This paper will examine the history of this country's Independent Living Movement, discuss the various types of Independent Living Programs and conclude by providing an outlook on future initiatives.

INTRODUCTION

> "It has shown me that there is a fundamental difference between merely existing and living for something brighter; the challenge of being individually responsible for my oactions." - Walter Zarnowski, first resident at Boston Center for Independent Living [Driscoll, J.V. Second Generation: New England, American Rehabilitation, Vol 3, p. 18, 1978].

Imagine the thoughts that go through someone's mind who is prevented from receiving a college education because he is in a wheelchair and the college of his choice is inaccessible; or imagine what it would be like to live in an institution due to the lack of appropriate, supportive, community-based housing. These thoughts and experiences are, indeed, not very pleasant.

The statistics indicate that one person in every 10 of the world's population has some form of physical, developmental, or mental disability, and for many of these individuals, situations such as the one's described above are an every day occurrence [Bruck, L. ACCESS: Guide To A Better Life for Disabled Americans. p. 9, 1978]. To work, have a home, raise a family, and share in the joys and responsibilities of community life are dreams that will never be realized.

The goal of an independent life for the disabled has given rise to a movement of disabled individuals, committed to seeking new living alternatives for themselves and others. This surfacing of awareness has led to the development of a variety of independent living programs. The most common are: Centers for Independent Living, Centers for the Handicapped, and Independent Living Residential Centers. This paper will focus on the "state of the art" as relevant to the goal of an independent life for the disabled. It will examine the history of the Independent Living Movement, discuss the various types of independent living programs, and conclude by providing an outlook on future initiatives.

RECENT HISTORY

The Independent Living Movement has been gaining momentum in the United States since the early 1970's. Its goals are the realization of basic

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*U.S. Department of Housing and Urban Development; Director, Office of Independent Living for the Disabled

human rights by reducing and, eventually, eliminating the physical and social barriers that prohibit the disabled from actively participating in society. This Movement is based upon the concept of Independent Living (IL) which, although quite broad in scope, implies a network of resources which allow an individual full participation in society despite his functional limitations, and enable him to experience greater control over his own life.

The Independent Living Movement emerged from a combination of interacting factors: the end of the Viet Nam War sending home thousands of paralyzed veterans; the deinstitutionalization process returning to the community those individuals capable of living independently in a supportive environment; and, the anger and frustration of the disabled who, for so long, have been treated as second class citizens. These pressures were building in a society that had no coordinated service delivery mechanism to cope with the reality at hand.

Increasingly, the disabled have taken it upon themselves to fill in the gaps existing in the service delivery mechanism. In 1962, two quadriplegic men were admitted to the University of California at Berkeley as part of an experiment which would allow them to live on campus, away from their homes. They were joined two years later by another quadriplegic student and in the following year, by five more similarly disabled students. All eight disabled students were housed in a medical setting which proved to be a catalyst for the initiation of changes at the college campus. By taking advantage of their eligibility for certain benefits, the students were able to hire personal attendants, reimburse the University for a substantial portion of their extra living and medical expenses, pay for their education, and have a little spending money left over. Thus, they were able to experience a more independent lifestyle. Housing in a medical setting was replaced with the preferred alternative of private, off-campus rental housing. In 1970, the group of disabled students received a Federal grant which enabled them to become providers of official University services to other disabled students and the UC Berkeley Physically Disabled Students Program (PDSP) was created. In 1972 PDSP evolved into the first Center for Independent Living (CIL).

CENTERS FOR INDEPENDENT LIVING

The Berkeley CIL was established as a self-help outreach program designed to expand options and alternatives available to disabled people. Now in operation for six years, the Berkeley CIL serves approximately 5000 persons representing a broad range of disabilities. The Center provides basic services such as family and peer counseling, mobility training, housing assistance, attendant referral and training, wheelchair repair, etc. Since 1972, over 30 Centers for Independent Living have been created across the country using the Berkeley CIL as a model. Although no two centers are identical, a Center for Independent Living can be generally defined as an independent living program that is nonprofit, controlled by disabled consumers, nonresidential in nature, and provides a certain specific set of services [Driscoll, J.V. op. cit. p.3]. Different funding sources, philosophies, organizational structures and goals make each center unique. There are, however, two basic commonalities that all centers share. First, each CIL has, as its purpose, to assist disabled individuals to live independently in the community, rather than dependently in institutions. Secondly, each center is based on an extensive amount of consumer involvement and control that gives people with disabilities the opportunity to plan and implement the decisions that affect their lives. Simply stated, the disabled are their own best advocates.

The following diagram illustrates how the various dimensions of the concept "independent living" are related [Texas Institute for Rehabilitation and Research, "Definitions Related to the Concept of Independent Living," unpublished paper, p. 7, 1978].

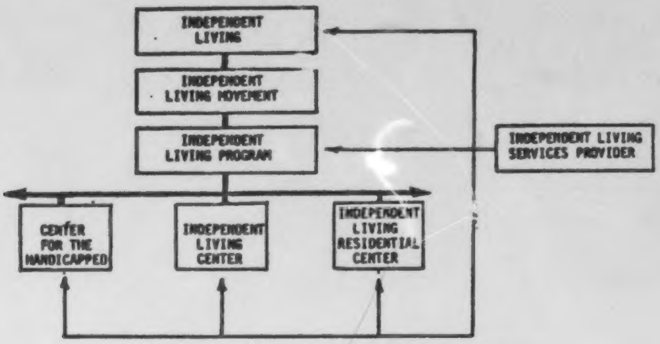
INDEPENDENT LIVING
INDEPENDENT LIVING MOVEMENT
INDEPENDENT LIVING PROGRAM
INDEPENDENT LIVING SERVICES PROVIDER
CENTER FOR THE HANDICAPPED
INDEPENDENT LIVING CENTER
INDEPENDENT LIVING RESIDENTIAL CENTER

FIGURE 1. FLOW DIAGRAM OF INDEPENDENT LIVING CONCEPTS AND ORGANIZATIONS

OTHER INDEPENDENT LIVING PROGRAMS

The Center for Independent Living is only one manner in which the goal of an independent life for the disabled has been realized. Independent Living Programs have taken other forms: notably, the Centers for the Handicapped and the Independent Living Residential Centers. As "independent living programs" these are both community-based programs that provide services; coordinate existing services; and/or list referral to assist severely disabled individuals in increasing personal self-determination and in minimizing unnecessary dependence on others.

A "Center for the Handicapped" is a single or multi-purpose facility which seeks to assist persons with disabilities to become more functional members of the community by providing programs or services which may include recreation, education, health care, social development, independent living, and physical and vocational rehabilitation. By utilizing the variety of service mechanisms already in place, a Center for the Handicapped can coordinate the delivery of services to the disabled through referral and advocacy.

Still another variation of an Independent Living Program is the Independent Living Residential Center which provides housing, attendant care, and transportation, rather than referral to these services.

THE ROLE OF SUPPORTIVE SERVICES

The concept of independent living is oriented toward the individual. Independent living programs should then provide only those services that are needed by the disabled individuals. Since the disabled population, like the able-bodied population, is so diversified, the variety of services needed and the extent to which they are provided must vary with each individual. For example, one disabled individual may need a personal care attendant to function to his potential, while for another individual, an accessible house may be all that is necessary.

Figure 2 is an excellent diagram illustrating the comprehensive service delivery system. All independent Living Programs play an active role in trying to assure that each segment is in place. In addition to working with the client, a successful program must work with and change an environment which creates physical and attitudinal barriers for a disabled person.

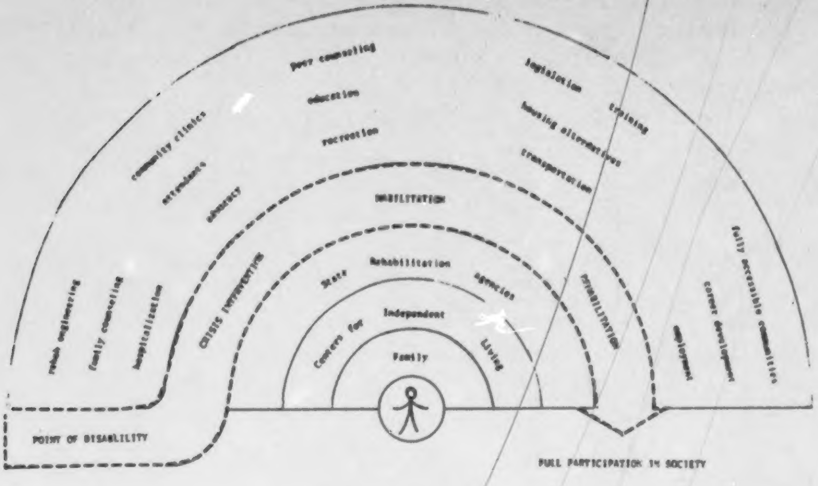
peer counseling
education
recreation
community clinics
attendants
advocacy
legislation
training
housing alternatives
transportation
INSTITUTION
State
Rehabilitation
Agencies
Centers for
Independent
Living
Family
rehab engineering
family counseling
hospitalization
CRISIS INTERVENTION
REHABILITATION
employment
career development
fully accessible communities
POINT OF DISABILITY
FULL PARTICIPATION IN SOCIETY

FIGURE 2. COMPREHENSIVE SERVICE DELIVERY SYSTEM

HOUSING OPTIONS

An integral element in the network of services is that of housing alternatives. Many disabled individuals capable of functioning independently are placed in nursing homes and larger institutions because of the lack of accessible and affordable community-based housing. This fact has caused the individual with a physical or mental impairment to be denied the right to live in the home and community of his choice. Included among the major impediments to the development of independent living programs is the insufficient variety of housing alternatives that would enable disabled individuals to choose an appropriate lifestyle compatible with their needs.

The Department of Housing and Urban Development (HUD) through its Office of Independent Living for the Disabled (OILD), has initiated several programs which will help to alleviate the housing crisis often confronting the disabled population. The responsibility of OILD is to ensure that the Department's housing and community development programs are responsive to the needs of the disabled in addition to providing new programs where deemed necessary. HUD's goal is to integrate the disabled among the rest of society by providing a continuum of housing options that are small in size and scattered throughout the community. To that end, percentages of new housing units constructed under the public housing and rent subsidy programs must be accessible to the physically handicapped.

Another HUD program that recently got underway is a demonstration designed to assist in the deinstitutionalization process of the chronically mentally ill. Fourteen states have been selected to participate in this unique program which will provide funds for the new construction or substantial rehabilitation of small group homes serving no more than 12 individuals, or independent living complexes comprised of six to 10 cooperative apartment units. The purpose of this program is to normalize the lives of the chronically mentally ill by providing a supportive environment which will enable these individuals to live independent lives in the community.

Through several other programs, HUD also facilitates the development of independent living programs such as Centers for Independent Living and Centers for the Handicapped.

THE FUTURE OUTLOOK

The Independent Living Movement in America has come a long way since its birth in Berkeley 16 years ago. Today, one can point to several positive events which indicate that the future looks bright.

1.) A very significant piece of legislation, the Rehabilitation Act of 1973, contains a wide range of benefits for the disabled population. Section 130 of the Act authorized the Secretary of the Department of Health, Education and Welfare to conduct a comprehensive service needs study of the most severely handicapped. As a result of this study, five independent living rehabilitation demonstration projects were funded to study the feasibility of methods designed to a) prepare individuals with the most severe disabilities for entry into a vocational rehabilitation program, and b) assist individuals who have no vocational potential because of disabilities too severe to improve their ability to live more independently. These projects exemplify some of the possible models which can be utilized to provide independent living services.

2.) Amendments to the Rehabilitation Act are being considered currently by Congress. If the amendments are signed into law, a new rehabilitation program would be established to deliver comprehensive services to severely disabled people needing multiple, continuing, and probably lifelong, services and treatment. It will also authorize a grant program to stimulate states to extend present services programs for the most severely disabled without vocational potential. The establishment of independent living residential models such as group homes will be encouraged through this legislation as well.

3.) Section 504, another segment of the Rehabilitation Act of 1973, was recently enacted. This provision specifically prohibits discrimination on the basis of handicap in all Federally assisted programs and activities. It will have the effect of breaking down many barriers which prevent the disabled from actively participating in all aspects of modern society.

4.) In 1975, the first national conference was held on Independent Living. A second national conference is scheduled for September 1978.

5.) Currently ongoing is an Independent Living Research Utilization Project to study independent living programs and to develop a means of disseminating information gathered in order to facilitate the future development of independent living programs.

6.) The first White House Conference on Handicapped Individuals which was held in 1977, declared the goal of Independent Living a national priority.

CONCLUSION

All the above initiatives support the fact that independent living is a medically acceptable, cost-effective, and rewarding alternative to long term, institutional care. The challenge for the expansion of Independent Living Programs in the future is to avoid creating mini-institutions throughout the community where disabled people are isolated from life experiences. The disabled in America have demonstrated that this can be done and that the goal of an independent life is no longer a dream.

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Seminar 2

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MEDICAL ASPECTS OF PRESCRIPTION OF THE WHEELCHAIR (Summary)

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INTRODUCTION

It is important to distinguish between the hand-propelled wheelchair and its medical aspects of prescription and that of the problems which are of importance considering prescription of electric wheelchair.

Several parameters must be taken into consideration, mainly those of safety, stability, manoeuvring facilities, weight, volume, appearance, price, added to the consideration of age of the person and also the person's helper, if needed. Other parameters, specific to the wheelchair's mechanical construction must be taken into consideration and one is astonished that they can be over nearly fifty if one has in mind, not only the anthropometric and physical needs of a disabled person, but also the ergonometric aspects which will, in fact, guide the choice of the wheelchair by the medical and social team, with the help of the patient himself or herself, which is of paramount importance.

One is also surprised by the abundance of litterature, especially the last ten years, considering all the aspects of the wheelchairs, either hand-propelled or electric with electronic controls. Fortunately, thanks to the more, but still insufficient available information, and a better choice, a counselling is much easier also thanks to the work of multidisciplinary teams throughout the World, associated with the benefits of being able to have, I should say afford, the unvaluable help of a rehabilitation engineer. Ergonomic and mechanical assessment is done nowadays in a few centers, still too scattered throughout the world. The result of these tests being most valuable for our guidance and also being of benefit for the manufacturers themselves in improving the product they are delivering.

A. THE MEDICAL PRESCRIPTION AND PROBLEMS IN THE HAND-PROPELLED WHEELCHAIR

1.- WHO should, in fact, guide the patient's choice, if choice there is, in counselling the disabled person on the choice of his wheelchair ? I, personnally think, as many others, that it is a teamwork, consisting in people who, at one degree or another, intervene in the medical rehabilitation, either for in-patients, out-patients, ready to give their expertise in cases who are also referred to them.

Unfortunately, there is often a lack of information and assessment, the handicapped people just given what there is in stock without really being preoccupied by, in fact, many social aspects and medical consequences.

2.- WHEN should such a guidance take place ? This is no real problem if the person has already been assessed in a medical rehabilitation department, this usually occurs, as the prescription time is concerned, towards the end of the medical rehabilitation, the patient having been shown all the different possibilities and able, most of the time, to make his or her choice, having, naturally, been offered the possibility of trying out the wheelchair at home, in the town, and considering also all transportation problems, taking into account that the chair will be light enough to be

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put into the car easily by the person or his helper.

As children are concerned, the parameter of age, comfort, the fact that the child is usually far more mobile than an adult, breakes things easier and also, has, thank God, a definite tendency to grow....., will be a challenge to all concerned, but, in fact, a rewarding one of the medical problems can be overcome and complications avoided.

On the other side, considering the people who are aged and aging, these are given wheelchairs without much consideration, which is highly regrettable, when they are getting out of hospital, or just given prescription by people who are unaware of their problems and do not realize, in fact, that a wheelchair is perhaps one of the technical aids which will allow an elderly person to stay in his or her normal environment and making life easier also preventing unnecessary hospitalisation.

I cannot help feeling as a doctor that, even with a patient wheelchair one should take in account the diagnosis factors, as well as that of prognosis, and life expectancy, especially with evolutive diseases.

As the diagnosis is concerned, one must also consider all the psychological factors a wheelchair can have for someone who is suddenly either permanently or temporarily confined to, and depending on it, for his or her mobility, as well as the problem of acceptance either by his relatives, not neglecting all the social aspects.

I would like to review some different problems, linked to differend groups of incapacities :

First of all, that of paraplegia. This can be medical or traumatic and there will be differencies, according to the height of the lesion : a) the upper type from T1 to T7 b) the middle type from T8 to T11 and, finally, the lower type of paraplegia from T12 to the sacral segments. If one takes the upper type paraplegia, one should not forget to assess the person's muscle strength, balance, spasticity, sensory disturbances mainly all areas of skin, not only in the sacral area but also the lower limbs and the trunk, keeping in mind the sphincter disturbances. Problems of posture, preventive and curative, therefore also comfort, must be taken into consideration and different solutions have been offered. As the middle type of paraplegia is concerned, one must also take in account muscle strength, balance, spasticity, sensory and sphincter disturbances but, here the patient is much more independant and his physical possibilities do meet with the average ergonomical parameters encountered in most of the recent types of wheelchairs offered on the market. As the lower type of paraplegia is concerned, the same parameters must be kept in mind, but very often the patient, especially in incomplete cases, will only need his wheelchair as an accessory help, being able to walk either with the help of callipers (which do incidently cause skin trouble when the person is sitting down) or crutches.

As quadriplegia is concerned, one can distinguish, in fact, the borderline between C5 and C6, according to the person's neuro-muscular possibilities and balance is concerned. Another problem is, naturally, the one of an accessory wheelchair for indoor use and its equipment, so that the patient is independant at home. In the C4 to C6 group, propelling a wheelchair is difficult and the person will need, at least, a good deltoïd and biceps. The C7 to T1 group, usually represents little problems as indoor possibilities are concerned, with or without special aids. Using the wheelchair outdoors might be a different problem, as well as travelling.

One thing, which must be kept in mind for these patients with insensitive skin below the level of the lesion is the problem of the pressure sores. As we all know, these are caused by pressure, shearing forces, temperature, humidity, and general bad health condition. Very often paraplegics have problems in raising themselves every ten to fifteen minutes, or forget about it, and the quadriplegic patient does not get, does not want to ask, or disturb, his helper when he has one, to relieve the pressure on the ischio-sacral or trochanteric regions by lifting him. This brings me, in fact, to discuss the cushion problems which have, until now, been rather neglected but are paramount, not only for spinal cord patients, but also for other people, including children, and the aged group of people. Nowadays many medical teams and engineers are trying to solve this problems and some cushions are quite good but still need to be improved.

As hemiplegia is concerned, one must consider several factors : age, etiology, remaining motor function, control of the wheelchair either with the use of two upper limbs, one upper limb or foot controls, special problems must be kept in mind such as the disturbances of the visual limitations, corporeal schema and the extent of cerebral damage. Spasticity in the upper and the lower limb with its deformities must be considered with the same care as for spinal cord lesions.

As C.P. and allied conditions are concerned, spastics represent 65 % of that population, athetoids 25 %, plus the other types of tremelous or ataxic movements which will complicate the whole picture. Other diseases must also be taken into consideration, such as Friederich's ataxia. Cerebral palsy is naturally a problem right from the start and is one of the most difficult concerning children problems as wheelchairs are concerned.

Rheumatic diseases do represent problems as well as they represent the highest percentage of the population needing wheelchairs : pain, deformities either of the upper limbs, trunk or lower limbs, and that also, -as we all do-, of aging with a progressive medical condition.

As progressive diseases are concerned, either of neuro- or muscular origin, one should not forget the challenging problems of multiple sclerosis, amyotrophic lateral sclerosis and progressive muscular dystrophy. Some solutions have been found in Canada (GIBSON & al., 1975) but there will always be a problem of comfort, assymetric progression of the disease. These elements must be constantly kept in mind.

The trauma sequelae, as amputation of lower limbs are concerned, represent no great problems, except that of comfort and ergonomic requirement, especially for people having had an amputation for the lower limbs for medical affliction but ergonomic considerations are very important with cardiovascular diseases and insufficiences.

One must always remember that a wheelchair is a beautiful instrument to cause deformities, sores and induce laziness.

B. THE ASPECTS OF THE PRESCRIPTION AND USE OF THE ELECTRIC WHEELCHAIR

One must consider the type of handicapped people who are mainly either high quadriplegics from spinal or several other origins with or without respiration insufficiency. Congenital diseases, progressive neuro-muscular diseases, severe rheumatic diseases and other disabilities are usually the reason also for their prescription.

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The psychological aspects, such as acceptance by the patients and his relatives, as well as social acceptance, must be kept always in mind.

There will also be other parameters, such as safety in the control possibilities, comfort, positionning, reclining backs and footrests, preferably patient operated.

The use of the electric wheelchair indoor and outdoors must also be evaluated.

Great progress has been made last three-four years in safety of the controls which must be proportionnal as start, acceleration, turning and braking are concerned, as well as parking brakes which must be, if possible, kept under the patient's control.

(Slides will be shown to illustrate different problems and some solutions)

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TRAUMATIC DISABILITY

RUSHED OFF MY FEET

ENID KING

ABSTRACT

RUSHED OFF MY FEET

ENID KING SRN SCM HV

Enid King fractured her spine in a car accident and, in a matter of seconds, her life was changed from a busy housewife and mother, caring for two young sons, to a disabled person permanently confined to a wheelchair.

A State Registered Nurse, Midwife, Health Visitor and now the full-time organiser of a day centre for the handicapped, she has endeavoured to view her subsequent rehabilitation with a professional attitude while experiencing all the frustrations and setbacks of any person in the same circumstances.

She shares some of the experiences and observations gained during her eighteen years in a wheelchair and discusses the importance of mobility and access when obtaining employment.

PERSONAL STORY

I have been in a wheelchair for eighteen years. Due to a car accident in 1960, when my spine was injured, I am paralysed from the waist downwards. At the time of the accident, I was married with two young sons of four and six years of age. My husband was driving and he and my two sons were involved.

Because of the nature of the accident, I received no financial compensation and, as a housewife, did not qualify for sickness or unemployment benefit.

My husband was self-employed, we had a mortgage on our house and we owned a car. Our sons had been accepted for a fee-paying preparatory school and we had planned that I should return to work to help with the fees. The future prospects were bright.

Our financial situation was changed overnight. We were not eligible for State assistance and our house was not adaptable for a 'wheelchair' housewife. It took a year to build a bungalow and during that time our dining room was used as a bedroom and I was carried upstairs once a week for a bath. The children had measles but I was unable to tuck them in bed at night or kiss them after they were asleep.

In order to maintain an ordinary household, we had to pay other people to do housework, gardening, decorating and repairs and we were unable to maintain the standard of living we enjoyed before I became disabled.

My husband's state of mind was a constant worry to me. He blamed himself for our situation and it distressed him to see me so disabled. He could not talk about the accident.

For my part, I felt I must do all I could to show him that life could still go on and that we could remain as a family unit.

Two years later, in 1963, my husband died of cancer at the age of forty-one.

Before my marriage, I qualified and practised as a State Registered Nurse, a Midwife and a Health Visitor. It seemed at this time that my training would be of no more use to me.

My children were sent to boarding school and I found employment for two mornings a week as a clerk at a Health Centre.

The Invacar provided by the Ministry of Health did not give transport for my two sons who were too young to use public transport on their own. To overcome this, I took lessons with the British School of Motoring and passed a test to drive a motor car with hand controls.

Increased mobility enabled me to obtain more employment and I taught Health Education and Human Biology at a Comprehensive School for two afternoons a week.

I remarried in 1967 but continue to live in the purpose-built bungalow because it is easier for my husband to travel fifty miles a day than it is for us to find suitable housing nearer to his employment.

For the last three years I have been in full-time employment with the Social Services as a Day Centre Organiser for the Handicapped.

The Chronically Sick and Disabled Persons Act of 1970 stated that wherever possible Local Authorities should provide Day Centres for the handicapped. Day Centres must be accessible for wheelchairs, which is a major problem when seeking employment, and this has given me the unique opportunity of combining my experience as a disabled person with my qualifications as a nurse and Health Visitor to what, I hope, is some benefit to the community.

My sons are now adult, one married and one living at home and I have just become a grandmother. I am still happily married to the man who was prepared to accept me and my wheelchair.

I invite you, now, to share with me some observations and experiences I have had during these eighteen years as a paraplegic.

NEWLY DISABLED

After six months in Stoke Mandeville, I returned home to a house that had three steps up to the front door, bedrooms and bathroom upstairs, an inaccessible telephone and kitchen equipment entirely unsuited to management from a wheelchair.

It was a desperate feeling of frustration when I realised that I would never again be able to look after my home and children without the help of

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other people.

How could I come to terms with the fact that some stranger would have access to all my personal belongings and know the intimacies of my personal life? That others would be witness to my clumsy endeavours to do things for myself, see me in moods of deep despair, know if I was incontinent or if I was having a menstrual period.

Never again was I going to be able to post a letter, go shopping, walk over the countryside, spring-clean, or take part in social activities without making a prior arrangement with an able bodied helper. Never again could I meet the children from school or take them on visits to places of historical interest. It would be somebody else who would have the joy of watching their reactions when they travelled on their first escalator, went on their first train journey or learnt to swim.

My dentist was on the first floor and the hairdresser up a flight of steps.

I had too many visitors who chatted but did nothing. I grew tired of explaining where to find articles that were upstairs. I was worried about urinary infection and I had no regular physiotherapy.

The situation seemed hopeless.

REHABILITATION

" 'Think positively'. Fill your day with the things you can do and put into the background the things that you can't." This was the very sound advice given by Sir Ludwig Guttman.

The patient suffering from temporary disablement such as a fractured limb, can indulge in self-pity, accept sympathy and feel that any service rendered by friends and neighbours can be repaid when full health and strength is regained.

Gadgets such as crutches, walking frame or wheelchair are a novelty and rather fun to try, especially as the 'invalid' image is for a limited time.

Permanent disability presents a very different picture. A permanently disabled person can feel well and healthy but the disability will remain the same. To come to terms with the fact that the disability is permanent and that life in the future must be limited to the activities that are possible, needs a discipline of mind that is not achieved overnight.

To change one's hobbies from horse-riding and dancing to toymaking and canework is not easy.

The ultimate goal of rehabilitation is, I suppose, for a person to be able to find a place in the normal everyday life of the community again.

The requirements of rehabilitation vary with the individual and depend upon age, sex, marital status and financial facilities.

In conditions of paraplegia, such as my own, a new way of life is developed gradually over several years and it cannot be achieved without the understanding and patience of able-bodied members of the community and the will to succeed.

For married couples, readjustment of sexual relationship is a difficult problem, very often with the complications of incontinence and uncontrollable spasms, in addition to paraplegia.

For the single person, the chance of marriage seems very remote and the prospect of living with parents who will continue to treat the disabled person as a child makes the future seem intolerable.

In most cases a return to employment, for the male, is the ultimate goal with recreational facilities for sport either as a spectator or player.

For myself, the role of housewife and mother needed to be reinstated. Cooking, washing and ironing the clothes and amusing the children had to take precedence over swimming sessions for the disabled, on a Sunday morning, which segregated me from the family and physiotherapy at the hospital, which prevented me being at home when the children were brought home from school.

PERSONAL HYGIENE

Whatever the circumstances, it is, to my mind, worth while spending time and energy in attempting to cope with one's own personal hygiene. To be able to wash my face, comb my hair and clean my teeth gave me a sense of real achievement and brought back a sense of personal dignity and confidence.

I was grateful to the helpers who gave me encouragement and to friends who helped me reorganise my wardrobe with garments that were washable, light in weight and durable. It was disappointing to have to discard my high heeled shoes and tight skirts, but it was important that my personal appearance was as pleasing as possible, in spite of the limitations.

Gadgets play an important part in the life of the newly disabled and I was surrounded by 'helping hands' of various types, stocking puller-uppers, zipp fastener hooks and bells, as well as lifting chains and calipers.

Part of rehabilitation is to learn to manage without gadgets because it is not always possible to carry them about and improvisations with ordinary household equipment, such as a broom handle, is sometimes more convenient.

MEETING THE GENERAL PUBLIC

Meeting the General Public as a newly disabled person takes quite a bit of courage.

People very often shout and presume that I am deaf or speak to me as though I am mentally retarded. They will ask my husband if I take sugar in my tea, even though I am sitting next to him.

Some people insist upon cutting up my bread and butter and I have been advised not to go out in the dark.

Some people are frightened of a disabled person and will not speak even though there is no one else about. I have learnt that I must speak first, to put them at their ease.

Equally disconcerting are the people who think they know all about me. They have a relative in a wheelchair and presume that everyone is in a wheelchair for the same reason. These are the people who grab my chair, take off my brakes and promptly tip me out at the first kerb they try to negotiate.

Quite a lot of people tell me the story of their operation and many will state that faith in God will enable me to walk again.

I am glad to say that my sense of humour helps me most of the time.

MOBILITY

Mobility brings a new degree of independence. Sitting at home looking at all the things I was unable to do and watching somebody else do them was boring and frustrating.

To drive again gave me a freedom of choice. I could stop in a country lane and look at the scenery. I could go shopping and I could visit friends. Even more exciting it gave me the chance to apply for a job.

I was employed for eight hours a week as a filing clerk at a Health Centre, which was accessible for a wheelchair.

It was my chance to prove that I could be reliable and capable of holding down a job. I had to accept instructions from Health Visitors less qualified than myself and listen with envy to their conversation when they had attended lectures concerning new techniques, which, as a clerk, I was not eligible to attend.

However, the compensations were enormous. I was in contact with people again - not just drinking coffee and gossiping but involved in giving a service, widening my horizon and earning some money.

This first job was the beginning of the long climb towards full-time employment as a Day Centre Organiser in which I am accepted on equal terms with my colleagues.

The difficulty of access to buildings still prevents the integration of disabled and able-bodied people who wish to pursue the same interest. I am concerned, however, that disablement is sometimes the only common denominator of a group of people. The lumping together of the physically and mentally disabled is most distressing for all concerned. The restricted physical activity imposed upon the mentally disabled is not necessary and for the physically handicapped the mental stimulus of intelligent conversation is unavailable.

I am also concerned that incentive to find employment is dampened when benefits such as the Mobility allowance or rate rebate are taxed if the disabled person earns above a certain amount in spite of the fact that it is recognised the day to day requirements cost more than an able-bodied person on the same wage.

During the eighteen years that I have been disabled a great deal has been done to improve the quality of life and a definite promise of a little help which is fulfilled means far more than a vague suggestion that a lot of help might be available. The very fact that this conference is being held shows how much more understanding there is now for the needs of the permanently disabled.

SPINAL CORD INJURY AND PEER COUNSELING/PEER EDUCATION

John E. Schatzlein

Self-help, peer counseling/peer education groups can aid individuals cope with and adapt to catastrophic illnesses and disabling conditions. Peer help, organized outside the traditional health care model, has been an important therapeutic modality for several decades.(1) Self-help groups such as Alcoholics Anonymous(2), Recovery Incorporated(3) (for patients with mental illness), TOPS(4,5) (Take Off Pounds Sensibly), Ostomates(6) (patients with colostomies and ileostomies) and Widow-to-Widow(7) are examples. It is time to include the peer helper in the traditional health care model.

TERMINOLOGY

I would like to define or present various terms associated with peer counseling/peer education. It seems that there is some confusion or there is a hesitancy to use one term over the other when we're dealing with the area of peer counseling. If we were to define terms like counselor, educator, professional, para-professional, advocate, we would see that a standard dictionary defines these terms similarly. All of us as individuals can and do at times, educate, counsel, advocate for, other people. Funk and Wagnell's Standard Dictionary International Edition defines counselor as one who gives counsel; an advisor. Counsel is defined as 1) mutual consultation or deliberation; 2) opinion or advice; 3) deliberate purpose; 4) good judgment or prudence; 5) a lawyer or lawyers engaged in a cause in court; an advocate. To advocate or an advocate is to speak or write in favor of; to defend; recommend; one who pleads the cause of another; an intercessor; a defender; a counselor. An educator is defined by the same source as a teacher. A teacher being defined as one who inparts knowledge by lessons; gives instructions to; guides by precept or example; instructs; makes known; communicates the knowledge of; to train by practice or exercise; to follow the profession of teaching; to impart knowledge or skill. Professional can refer to a person of or pertaining to a special occupation often for gain; one who persues a business or some vocation/occupation.

As we can see by the definitions, there is much cross referencing to each of the words and we must accept that individuals may be counselors, educators, professionals, and that each of us based on our own walk of life, our own education, both formal and social, have within us the capacities or the potential capacities for sharing our experiences as educators, as counselors, and as professionals.

As we look at peer counseling and professional responsibility, I look to Allen's (1973) presentation before a group of his fellow professionals(8 He indicated that the peer counselors, the non-professional, sub-professionals, or as Eisdofer and Golann (1969) refer to them, "the new professionals" are now found in free clinics for the street people, juvenile detention centers, nursery schools, day care centers, crisis intervention

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centers, state hospitals, drug rehabilitation programs, poverty agencies, hospital rehabilitation centers, and many other agencies.(9) One would be hard pressed to think of many areas of mental health work that are not being handled by people with far less than professional credentials. We are truly in the midst of what Francine Sobey (1970) calls in the title of her book, "the non-professional revolution in mental health."(10) As Allen goes on to point out, the explosive increase of para-professional personnel numbering many tens of thousands raised tricky issues for those of us who have professional investments in the health field. All of us can feel a deep sense of responsibility for the standards of our profession and for the public good.

MODEL

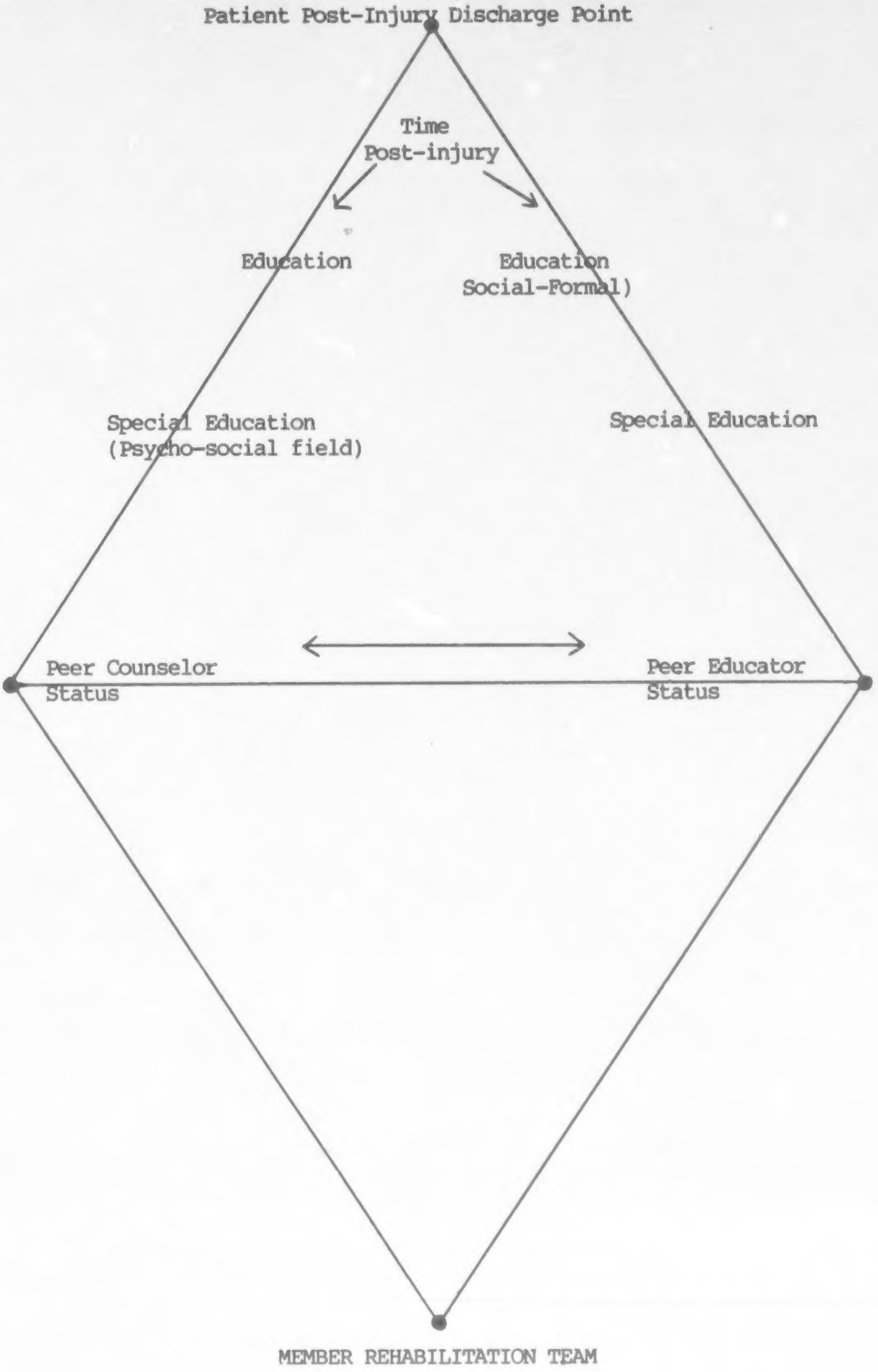
(Diagram I)

As we deal with the area of peer counseling, it has become evident that, based on the professional definition of counseling and the role that counselors have assumed within the psycho-social professions, we need to look at perhaps two different types of peer helpers. One is termed "peer counselor". This disabled person has obtained training, skills, and practice in the area of counseling. The second person being a person I would define as a "peer educator". A model I use tries to show the inter/intra workings of the peer counselors/peer educators. Having acquired a catastrophic illness or disabling condition starts the top of a triangular model. As the peer counselor/peer educator becomes more involved in their own lifestyles, they choose to go onto specific professional counseling education, or choose to go onto perhaps another type of job or professions not equated with the psycho-social or teaching professions. Each has also acquired years of experience having had a medical illness or permanent disability, they have reached a point in their life when the skills that they've learned concerning their disability may qualify them as a peer educator, teaching a newly disabled person perhaps things like how to transfer most efficiently, how to get dressed or deal with activities of daily living functions most effectively or how to drive, or what type of vehicle to buy or what kind of house remodeling is necessary. These peer educators should be of minimal threat to the psycho-social health care professionals because what they teach really do not have counseling connotations. The peer counselor, on the other hand, would be a person who has gone through educational training, a person who has acquired the skills to do the more traditional counseling practices. It is as possible to have a peer counselor who is also a peer educator as it is to have a peer educator, who under supervision of counseling staff, take on some supportive counseling roles during their educational tasks. Referring back to the definitions of counselor, educator, advocate, we must recognize that there is a closeness in the definitions, an intrachangeability in the redundant terminology.

RESPONSIBILITIES

As peer counselors/peer educators, one has the responsibility in his relationship with the patient to recognize that the patient is an individual, that the patient does not need to be like the peer counselor or the peer educator, that the patient does not have the advantage of months, or years of experience as a disabled person. The first responsibility of the peer counselor/peer educator is to take the patient as a person as all should in the health care profession. We should not set

PEER COUNSELOR - PEER EDUCATOR (Diagram I)


Patient Post-Injury Discharge Point
Time
Post-injury
Education
Education
Social-Formal)
Special Education
(Psycho-social field)
Special Education
Peer Counselor
Status
Peer Educator
Status
MEMBER REHABILITATION TEAM

up goals and expectations for the patient based on what we had set up for ourselves when we were patients or the goal we have set up for ourselves now. The responsibilities to the staff, the psycho-social health team, are similar in that we should not assume a hard line territorial rights stance. We should not negate the role that they play in the rehabilitation process. We should not, because of a lack of disability, assume that they have no knowledge about disabilities and about avenues by which a disabled person can better cope with and adjust to their disabling condition. They as staff and psycho-social health team members should not negate the contribution that a former patient has to offer relating to education and also to peer counseling.

As professionals in rehabilitation, we all should recognize that the medical model has been used as the key model for years. We're beginning to see and realize that physicians around the world should not have to be and are not gods. We are beginning to recognize and need to accept the fallibility of each other. We must assume the responsibility of relying on each other.

A spinal cord injury can completely change the lifestyle of an individual. It can change one's outlook on life completely. It creates medical, psychological, social, vocational, and sexual turmoil, often lasting a very long time. There is work enough for all professionals, peer counselors/peer educators associated with a spinal cord injured patient and their families.

Peer counselors/peer educators have been trained and effectively utilized to deliver a variety of services in rehabilitation, habilitation settings. Assisting in sexual education and sexual adjustment is one example of peer professional usage.(11)

Some specific professional responsibilities are pointed out by Allen.(12) Allen indicates that there are seven areas that the professionals, physicians, psychologists, social workers and others have when working with peer counselors/peer educators and para-professionals. The first of these responsibilities is the overall planning of training and service programs seeking the participation and the utilization of the peer counselor/peer educator. As he indicates, "days are long past when experts could be certain that they alone know what is best." (Allen, 1973, page 339)

The second responsibility is in the development of role definitions, that is, the specification of job functions, expectations and limitations for the para-professionals in the program. There needs to be joint discussion as to how the para-professional peer counselor/peer educator will fit into the care delivery team and specifically what are some of those expectations and limitations of this individual. It is, however, the responsibility of the health care professional to help the para-professional peer counselor/peer educator assume greater responsibilities. The reasoning behind this is that the para-professional peer counselor/peer educator has experienced the disability or catastrophic illness and that is of value. Sharing, teaching and assisting a newly disabled individual can often be done more effectively when one knows or is more in touch with what the person is actually going through or what the person has gone through.

A third area of responsibility is in developing training functions for the professional and the para-professional, to assist in training, teaching and supervision of the peer counselor/peer educator.

Fourth is client acceptance. It is a part of our responsibility to make sure that there is a market for para-professionals. In other words, what we need to do is recognize that the para-professionals are of value in all facets of the health care system. We must do what we can to eliminate barriers to the usage of this particular professional. We need to resist the impulse to convert para-professionals into junior editions of ourselves.

Another responsibility that we have is to help insure career mobility. This means we must be able to provide for an opportunity to move up to higher levels of education and to positions of greater challenge and that means that the professionals must be willing to see some of their best trainees and some of their best peer counselors leave, and by leaving, facilitate the growth of other peer counselors/peer educators. As this is carried out further it begins to deal with the areas of licensing, examinations, perhaps of accreditation, but at this point in time, it is appropriate to begin to deal with the beginnings of acceptance and use of peer counselors/peer educators.

The sixth area gets into the sensitive subject of monetary compensation. Often times a peer counseling/peer educator is not given any renumeration for the work that he/she does. They are looked upon as purely volunteers. It is indicated to them they ought to feel proud of what they're doing and that should be enough reward. As the person who is the peer counselor/peer educator becomes more skilled and is used more often, it becomes evident that they are professionals and that being a professional means that they ought to be compensated for the work that they have learned, and for the occupation that they have undertaken. In some programs that have been described by Sobey, (1970) some para-professionals have risen to the challenges of the hierarchy by joining and forming unions demanding pay rates comparable to those of the professional levels. Allen further says, "those of us who are professionals should constantly be looking at and checking with ourselves to determine if the credentials that we now have in our hands are really valid. Which of us is better able to serve the new client population, the addicts, the elderly, the urban ghetto minority groups, the disabled."

As para-professionals emerge as a major force within the health field, it is evident that they will be taking on more and more important functions in all sorts of settings. We are beginning to see that para-professional peer counselors/peer educators are better able to relate to certain client groups than can some able-bodied professionals and are able to exercise more relevant leadership in community action programs. It would not seem surprising, then, that they ask for appropriate recognition and compensation.

Finally, the seventh area of responsibility we have as professionals is a different kind of professional responsibility and that is legal liability. The whole area of legal liability is a very difficult area to deal with. More and more people have access to lawyers, more and more people have access to representation of all types and it would seem necessary to look at the area of legal liability as we begin to more openly use and train peer counselors/peer educators.

We must all begin to work at the elimination of fear and of prejudices towards peer counselors/peer educators. I would hope that we could break down some of the traditional medical cure-all models and begin to trust one another. I would hope that the physicians would be able to recognize that with the complexities of society today, with the complexities of the entire health care delivery system, that there are professionals at all levels, in a wide variety of occupations. Physicians cannot be replaced, nor can the medical physician be expected to be a psychologist, a social worker, or a peer counselor. Likewise, the peer counselor/peer educator cannot be expected to be a physician, a social worker, a psychologist, a physical therapist, or an occupational therapist. Each of those fields demand a certain training and a certain amount of education based on the demands of that profession. It is necessary, however, to recognize that all are professionals and that all are necessary for the complete rehabilitation of a spinal cord injured person. Because we are aware of the changes that may occur in the lifestyles of the individuals with catastrophic illness or disability we recognize that team work will be the major tool necessary in preparing the newly injured individual and his family for the world outside the hospital and to prepare them for the whole re-entry process into the community. Our job and task is to assist with the development of coping skills leading to adjustment, leading to attainment of an acceptable, satisfactory lifestyle for all. This task is a huge one. To obtain it, we must all recognize each other's skills. We must eliminate distrust. We must eliminate oversized egos. We must share and complement each other's abilities and in doing so we will form a truly united, resourceful team for the betterment of all spinal cord injured persons and for the betterment of all mankind.

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28 - 38 GROVE ROAD: ACCOMMODATION AND CARE IN A COMMUNITY SETTING

Ken Davis

ABSTRACT

28 - 38 Grove Road is a small, carefully designed and equipped scheme of flats in an ordinary community setting which offers an alternative to institutions for severely physically handicapped people. Able-bodied 'supporting families' - who have no special training or qualifications in working with the disabled - co-operate together to provide the kind of secure, flexible support normally unobtainable from statutory domiciliary sources. The scheme was initiated by people who had suffered traumatic spinal injury resulting in tetraplegia. The concept of the scheme was a reaction to segregated institutions and the ideas underlying it developed out of an analysis of their own experience of institutionalisation. The scheme, which took four years to get off the ground, was built by Inskip St Giles Housing Association (now Raglan Housing Association). Architects from the Wyvern Partnership worked closely with the handicapped tenants from inception to completion.

INTRODUCTION

In Great Britain we have a habit of providing for 'difficult' minority groups in segregated institutions and those suffering traumatic tetraplegia are no exception. It is a tradition which has roots in the Poor Law and which comes down to us today virtually unchanged. Only rarely can someone who depends heavily on others for personal help, and who for some reason does not have the support of- or wishes to live independently of - his or her family, find an alternative system of accommodation and care. 28 - 38 Grove Road is a fresh approach and this paper attempts to convey a little about the tenants view of the scheme; the objectives it set out to achieve; and how the scheme works in practice.

PHYSICAL FEATURES

On the surface, 28 - 38 Grove Road appears merely to be a group of six fairly ordinary two storey flats. They occupy a corner-plot at the junction of Grove Road with another undistinguished street in a typical Midlands industrial town. Underneath however, things are not quite as ordinary as they at first appear.

The three ground floor flats are specially designed for occupation by physically handicapped tenants. They are linked to the three first floor flats by a speech intercom system which is sufficiently flexible to allow any given tenant to communicate with any other tenant in the building. The upper flats are designed to be let to the ablebodied 'supporting families' who are willing to co-operate with all the other tenants in providing a background of personal help to those tenants who happen to be physically handicapped.

Founder member of the Disablement Information and Advice Line and active member of other disability organisations.

The interior design of the ground floor flats contains features nowadays becoming more common in 'wheelchair housing.' For instance, the corner worktop in the kitchen allows access to sink and hob unit without the need to move position. But the generally unobtrusive nature of the design features and items of equipment tends to conceal the careful thought underlying them. The level top of the hob allows hot pans to be slid across to the sink - an important point for people with paralysed hands and fingers. And details such as the shape and sizing of knobs, switches and handles were all important for the same reason. The electric hoist, in combination with the integral WC/douche, exerted a considerable influence on the design of the units. It was necessary to provide a method of transfer from bedroom straight to bathroom and thus the track hoist dictated the relationship between these two rooms.

There are too many design details to enumerate here, but it can be judged from this very brief description that a good deal of effort was made to create an environment which would enable the fulfilment of a specific goal. That goal was to provide a living situation for people hitherto considered too physically handicapped to live in their own homes in the community. It hinged on the simple idea that there should exist ordinary families willing to co-operate with disabled people in providing support not otherwise available.

OBJECTIVES

The immediate reason for the development of this idea stems from an attempt by a tetraplegic couple, and others, to find a practical solution to their accommodation and care problems which could enable them to get married. Marriage, in itself, is still a fairly familiar story - but dependent, handicapped couples approaching such a point in their relationship, rarely carry it through. Without going into personalities, that was not the chosen approach. As a consequence, there began a long and sometimes very difficult search for the solution which is the subject of this paper.

The character of this solution came about for a number of definite reasons. I have already noted the propensity in our society to provide the socially neat and tidy institutional means of solving the accommodation and care needs of dependent handicapped people who may be without family support. It is probably not surprising to find that some of the disabled people initially involved in the concept of this scheme were already in institutional care, and that the concept was a reaction to that situation.

With this in mind, it is interesting to refer to the objectives formulated by the disabled (then prospective) tenants of the scheme. They attempted to analyse the situation they were in, drawing out what they saw to be desirable objectives, as follows:-

(1) Institutions disable physically impaired people by taking them out of the community and aim to cater for their physical needs in batches, under the same roof and under the same regime.

Thus the design of the scheme should not make the building stand out as 'special' for the disabled and should blend into the local community. It should cater for handicapped tenants' physical needs in the privacy of their own homes, in a way which encouraged and supported their independence and individuality.

(2) Institutions are provided ostensibly because, in the absence of family support, statutory domiciliary services are insufficiently

comprehensive and flexible to meet the physical needs of severely handicapped people in their own homes in the community.

Thus the community based alternative had to embody a system of help sufficient to make up for the deficiencies in locally available services in meeting tenants' physical needs.

(3) Institutions have a hierarchy of paid staff who organise and provide help which is theoretically available to inmates all the time - whether or not it is wanted by them, or appropriate to their real needs.

Thus the help provided in the scheme should correspond to the help needed. The handicapped tenants should best know their own physical needs but, since any dependency situation involves a relationship between helper and helped, the organisation of - and payment for - help should be decided co-operatively between the people concerned.

(4) Institutions are dependency oriented. Staff see themselves primarily in a helping role and inmates as the dependent recipients of care. Comprehensive aids to independence are rarely provided or, if provided, used, by either residents or staff.

Thus the scheme should be oriented towards independence through inter-tenant co-operation. Helpers should see themselves primarily in a supporting role, and aids and equipment appropriate to the individual needs of handicapped tenants should be provided.

(5) Institutions occasionally allow inmates the opportunity to present limited views on aspects of organisation. But fully democratic participation in areas where inmates can usefully contribute is often actively discouraged.

Thus there should be maximum opportunity for all tenants to bring their personal resources into the scheme and exercise effective democratic control in clearly defined areas over their living situation.

The initiators drew on their wider experience of disability in formulating guiding principles to help them gain these objectives. Aware that disabled people and their families frequently have to put up with what other people thought best for them, they decided to rely heavily on their own experience in formulating an answer to their problem - and seek to create the conditions for consultation and participation with any party who could help them produce a solution.

ASPECTS OF PARTICIPATION

Four years elapsed from inception to completion, an eventful period which holds a story of its own. There were key events along the way: gaining the interest and co-operation of the (then) Inskip St Giles Housing Association; obtaining the agreement of the local church to the sale of the site of the derelict St Bartholomew's Mission; gaining loan sanction from Ashfield District Council; receiving the support of the Social Services Department; and participating with the architects of the Wyvern Partnership on aspects of the design.

The Architect's view on the value of participation is very clear. He notes that contact with the real client (the user) as well as the actual client (the Housing Association) is of the greatest assistance in solving problems which otherwise would be left to the architect to work out in unsure isolation. He observes that, in the Grove Road project, having contact with the spokesman and co-ordinator for individual requirements (one of the tetraplegic tenants) was particularly helpful in providing detailed solutions for those tenants who were known in advance.

But problems can follow from this point about known potential tenants for schemes in process of development. For tenants there is the real problem of holding a number of people together over a long period, where the hope of a tenancy lies at some unspecified future date. The Architect, aware of this problem, notes how important it is to adopt plan arrangements and fitment details which are sufficiently flexible to allow for changes of prospective tenants. For the Housing Association, there is the possibility that a given participant could develop views different from those of the other prospective tenants on how the scheme could operate and, notwithstanding, attempt to lay legal claim to the implicit promise of a tenancy. All of these problems had to be faced during the development of the Grove Road Scheme. With the benefit of hindsight, it is important that everyone connected with innovatory schemes should be agreed on and subscribe to the concept and objectives as early as possible in the development.

THE SCHEME IN OPERATION

The scheme has now been operating successfully for two years. During this time the tenants have dealt with matters of common interest through the medium of their association, the St Bartholomew's Tenants Group. The main business handled by the Group concerns the management of services to the common parts of the building, various functions which serve to foster good neighbourly relations in the local community, the organisation of, and payment for the 'supporting family' element of the support system, and initial tenant selection. Concerning the latter, advertising for, and initial screening of potential incoming tenants is conducted by the Group, who then make recommendations to the Housing Association for follow-up in accordance with their own tenancy selection procedures. Meetings of the Tenants Group are also a general forum: a medium for mutual education of individual and group needs.

Clearly it is necessary to have the right tenants, who understand the concept and objectives of the scheme, if it is to function properly. Because of the importance of this, special conditions of tenancy were drawn up which make it clear that occupancy of all flats in the scheme is dependent on all tenants accepting a co-operative basis of giving and receiving assistance.

The support system gives an indication of the extent of fall-back in the event of care failure at any point:-

(1) Locally available statutory services, eg, District Nurses and Home Helps.

(2) Three supporting families co-operating with the handicapped tenants to give help not covered by statutory services.

(3) Local voluntary support,eg, WRVS, the Community Service Scheme and local schools community projects.

(4) Neighbours, relatives and friends living locally.

(5) Selective hire of agency nurses.

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However, the handicapped tenants regard their own self-sufficiency as the first line of support. But overall, the intention is to 'spread the load' and avoid the typical situation which arises where there is disability in the family, where breakdown occurs because of the unremitting strain borne principally by one or two people.

It has never been necessary to resort to the fifth tier, and it is interesting to note that the disabled tenants greatly over-estimated the amount of help they would need. The case of the tetraplegic couple is typical: prior to moving in, and based on their experience of institutional care, they anticipated a combined weekly need of 2 hours from the District Nurse, 4 hours from the Home Help, and almost 20 hours personal help from supporting families. From their first day in residence, they were able to manage without help from the District Nurse. Whilst their assessed need for the services of the Home Help was realistic, their call on supporting families in the first week totalled only 8 hours - a figure which gradually reduced to an average of 1½ hours a week by the end of the first year.

Nevertheless, the de-institutionalisation process is difficult and exhausting: breaking conditioned dependency patterns does not happen without effort. Many factors help the process along however, including a degree of individual motivation. But plain, practical considerations lie at the heart of the matter. Good basic design coupled with aids and equipment appropriate to individual needs, reduce the need to call for personal help and maximise potential for independence. This in turn maintains harmony within the scheme: calls for assistance are seen to be necessary and supporting families know they are not simply being 'used'.

Examples of new-found independence are many: typical is the example of two female tetraplegic tenants. Over a combined institutional experience of 23 years, neither had ever dressed or undressed or been able to transfer to or from wheelchair to bed or WC. Now, using the track hoist in conjunction with ingeniously designed clothes and fastenings, both perform these functions completely independently. Or again, people previously considered too disabled to look after themselves, now prepare and cook meals as a matter of course.

The 'supporting family' element of the support system is readily adaptable to meet changing needs. These needs now consist mainly of help with shopping, small emergencies, minor help with dressing, and other personal needs. Still important for handicapped tenants is the security of knowing that there is always someone available to help, if necessary. A payment system has evolved to compensate the first floor tenants for help given and inconvenience caused.

As the tenants have remarked: a touch of flair and a lot of know-how on the part of the Housing Association, combined with patient, empathetic co-operation on the part of the architect, has gradually turned a simple idea into a reality. That reality is a home of their own, on the same terms as other people - and the benefits are almost beyond calculation.

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DISABILITY, ADJUSTMENT AND FAMILY LIFE -
SOME THEORETICAL CONSIDERATIONS

MICHAEL OLIVER

(a) Introduction

This paper will compare and contrast two theoretical approaches to the problem of adjustment to disability. It will argue that the psychological approach has so far dominated to the comparative neglect of the impact of disability upon family life and upon non-disabled members of a disabled person's family. An alternative sociological approach will be advanced and it will be suggested that such an approach must be much more broadly based and take into account social situations as well as individual experiences.

The concentration on theory and the polarisation of two alternative frameworks considerably simplifies both the scope of personal experiences and the complexities of theoretical frameworks. However, it is the belief of the author that what follows may be simplified, but it is essentially accurate.

(b) The Psychological Approach

A number of psychological theories have been utilised in studying how individuals cope with the onset of disability, albeit as the result of sudden trauma or progressive and ongoing debility. Personality theories (1), body-image theories (2), motivation theories (3) and interpersonal theories (4) have all provided the starting point for a variety of empirical studies. All of these theories have one thing in common - they assume that the onset of disability does not just bring about physical changes, but also changes of mental function. The mind has to adjust to these bodily changes. Hence an individual's personality must alter to come into line with his changed status or role, or he must come to terms with a changed or defiled body-image, or he may make greater or lesser efforts to achieve his goals in spite of or because of his disability, or he will have to adjust to the different way he is treated in interpersonal relations with others.

Starting from this assumption that something happens to the mind as well as to the body, a number of psychological mechanisms of adjustment have been identified, or more appropriately borrowed from other areas such as death and dying. Disabled individuals are assumed to have undergone a significant loss and as a result depression may set in. In order to come to terms with this loss, a process of grieving or mourning will have to be worked through, in similar manner to those who must mourn or grieve for the loss of loved ones. Only when such processes have been worked through can individuals cope with death or disability.

Some writers have seen these mechanisms as a series of stages or steps which have to be worked through. A recent study (5) in New York University Hospital identified a four-stage process by which newly disabled paraplegics come to terms with their disability.

Stage 1 - Shock - the immediate reaction to the physical and psychic assault of spinal cord injury often characterised by weeping, hysteria, and occasionally psychosis with hallucinations.

Stage 2 - Denial - a refusal to accept that complete recovery will not take place.

Stage 3 - Anger - often projected towards those physically active around them, who serve as constant reminders of what has been lost.

Stage 4 - Depression - a realistic and most appropriate response to a condition of severe and permanent disability and a necessary stage if adjustment, rehabilitation and integration are to be achieved.

Albrecht (6) characterises this and various other schemes as developmental models and argues that they all, at least partially assume that:-

(1) an individual must move sequentially through all of these stages to become fully socialised;

(2) there is but one path through the stages;

(3) an individual can be placed clearly in one stage by operational criteria;

(4) there is an acceptable time frame for each stage and the entire process;

(5) movement through the system is one way, that is, the system is recursive.

There are a number of general criticisms that can be levelled at those theories or explanations. Firstly, the model of man which these theories implicitly draw upon is one where man is determined by the things that happen to him - the adjustment to disability can only be achieved by experiencing a number of these psychological mechanisms or by working through a number of fixed stages. Secondly, adjustment is seen as largely an individual phenomena, a problem for the disabled person, and as a consequence, the family context and the wider social situation are neglected. Finally, such explanations fail to accord with the personal reality of many disabled people, particularly those with traumatic spinal cord injury, who may not grieve or mourn or pass through a series of adjustment stages.

Despite these criticisms, it would be true to say that these theories have been the dominant mode of explanation and this needs to be explained. A major factor in this is that these theories are in accord with 'the psychological imagination' in that theorists have imagined what it would be like to become disabled, assumed that it would be a tragedy and hence decided that such an occurrence would require difficult psychological mechanisms of adjustment. However, the psychological imagination may not be an appropriate starting point for such theorising or research - it is surely a value judgment to assume that disability is a tragedy and scientific research should be objective and value free. Another factor is that these explanations are individualistic and thereby politically convenient. When a disabled person fails to internalise the rehabilitation goals set by the professionals or persistently pesters his local Social Services Dept., he can be characterised as having problems in adjusting to his disability. This conveniently leaves the existing social world unchallenged; the goals of the rehabilitator remain unquestioned and the failure of the welfare department to provide the right assistance can be ignored.

While these and other factors may explain the adherence to these psychological theories, they do not explain why these theories have been empirically validated by a number of studies. I want to suggest that these theories become self-fulfilling in at least two ways. At a methodological level, having conditioned research in the sense that they posit adjustment to disability as a problem, researchers then ask questions relevant to that problem and get answers which are then presented as findings, valid social facts. To my knowledge, there have been no studies which started out with the assumption that disability was not a problem. The following quote (7) nicely illustrates the point:-

> "Reflection on the many problems to which the cord injured person must make an adjustment impresses one with the gravity of the psychological processes which occur following cord injury.

> Such an individual is confronted with grieving over his loss, coping with pain and phantom sensations, alterations in sexual functioning, loss of bladder and bowel control, the frustrations of immobilisation, loss of vocational goals and earning capacity, feelings of uselessness, role reversals in the family and the attendant loss of self-esteem and the social stigma of being 'different' in the public eye. It is an amazing tribute to the flexibility and magnificence of the human spirit that so many people whose lives are thus devastated survive and function at the level of physical and social independence which most cord injured people achieve." (My underlining)

As so many paraplegics are able to function at a reasonable level, it is surely more logical to assume that this is a normal everyday reaction and need not be described in such glowing terms. To put the matter simply, adjustment may be normal and not a problem at all.

There is a second way in which these theories may become self-fulfilling in that they may actually create the reality they purport to explain. In the case of mental illness it has been shown (8) that psychiatrists impose their definitions of the reality of particular problems upon their patients. Similarly in the study of criminal behaviour it has been shown that criminals will often verbalise theoretical explanations as excuses for their behaviour even in compulsive crimes like pyromania, kleptomania and child molesting (9). With regard to disability, many disabled people will have contact with the theories described above not through meeting academic psychologists or participating in research projects, but through the everyday contact with professional workers who are also internalising these theories. Professional journals are beginning to disseminate these theories widely. An article in Occupational Therapy (10) argues not only that individuals must experience the following phases of shock, denial, turbulent aggression and working through, but also that there are a number of adaptions that patients must make including adaptations in body-image, adaption in role-image, loss of security and loss of self-esteem. A recent article in Social Work Today (11) expressed the following sentiments:-

> "Patients must be allowed to come to terms, they must grieve and mourn for their lost limbs, lost abilities or lost looks and be helped to adjust to their lost body-image. Personally, I doubt if anyone who has not experienced the onset of irreversible disability can fully understand the horror of the situation."

What is being argued is that the psychological mechanisms and processes that research has identified and described are themselves the product of that research activity both as a result of its methodological predispositions and the spread of this knowledge to professionals who are then able to impose this definition of reality upon their clients. Indeed, these psychological theories have taken on the attributes of what one writer (12) has called a 'paradigm' - that is, a body of knowledge to which all those working in the field adhere. However, the same writer has shown that paradigms are sometimes replaced or overthrown by 'revolution' and this revolutionary process is often sparked by one or two critiques of the existing paradigm.

Thus far, a critique of the existing paradigm has been attempted; what follows will be a preliminary attempt to map out an alternative theoretical framework.

(c) The Sociological Approach

The alternative theoretical scheme to be advanced is based on a sociological theory known as 'symbolic interactionism' drawn largely upon the work of an American social psychologist, G.H. Mead, and some of his students (13). The two essential components of this theory are 'process' and 'meaning' - the experiences which individuals have, the things that happen to them are not fixed or stable, but rather take the form of a process through which individuals can negotiate their own passages. Further, these negotiated passages are not determined by the events that occur (like paralysis as the result of accident) but only by the meanings that individuals attach to these occurrences. These meanings are not themselves solely the product of individual consciousness, but are arrived at as the result of interactions with other people, close relatives and friends and the public at large; to use the language of symbolic interactionism, significant and generalised others.

The crucial question then is: what kind of explanatory framework does this scheme provide for those who become disabled as a result of injury to the spinal cord? Firstly, it sees the individual as a free agent in his own destiny - not in the sense that he can choose whether to be paralysed or not, but in the way he regards his paralysis. He does not have to experience certain psychological mechanisms nor follow any set of fixed stages - his adjustment will depend solely on the meaning he attaches to his social situation. He may experience some or all of these feelings identified by the psychological explanation, but he does not have to - he can regard his paralysis as a disaster or a triumph, but there are no basic processes which he must work through. Additionally, he may become depressed or grieve or mourn many years after he becomes disabled and not immediately after trauma. His feelings will be related to his particular social situation rather than his physical condition. Secondly, the meaning that disability has for particular individuals will be created in interaction with both significant and generalised others. Within symbolic interactionism, the term significant other (14) refers to those individuals or groups who can have an influential effect on what meanings an individual may attach to his particular situation. On the other hand, the term generalised other (15) can be taken to mean society, the general public or public and social attitudes. What needs to be considered then are the effects that both significant and generalised others may have upon the meaning of disability for individual paraplegics.

With regard to significant others, there are two kinds who may be influential. To begin with there are those professionals, doctors, nurses, physio and occupational therapists, whom the paraplegic will encounter during his stay in a spinal unit. They will generally put forward a positive view of the nature of paraplegia and stress such factors as personal independence, the ability to work, drive, compete in sport and so on. Hence psychological adjustment is not usually regarded as a problem in spinal units and few, if any, special arrangements such as the provision of skilled counselling or psychiatric assistance, are usually made.

Then there are others like husbands, wives, close relatives and friends, children and so on, who may not have such a positive view of the nature of paraplegia and issues like the management of incontinence, the problem of sores, the adequacy of finance, inaccessibility and immobility may provide the crucial meanings of paraplegia.

In relation to the creation of meaning in interaction with the generalised other, the way society treats disabled people is the crucial factor. At the level of social consciousness it would be possible to argue that the meanings associated with paraplegia are positive. However, at the level of individual interaction where meanings are created, these positive attitudes are not carried through. High rates of unemployment (16), a mean and stigmatising benefits system, a collapsing medical service and poor social service provision provide an everyday reality very different from that which might be suggested at the level of social consciousness.

Thus, within this theoretical framework, the meaning that disability has for individual paraplegics is created and negotiated in interaction with both significant and generalised others. In these interactions and negotiations positive and negative meanings may exist side by side, conflict and change temporally. The individual may exhibit many of the mechanisms identified within the psychological paradigm, however, not as a direct result of his disability nor in a necessarily ordered sequence, but as the result of his changing social circumstances and situations and the variety of positive and negative meanings that this gives rise to.

In line with the title of this paper, our central concern is with the family and the effect that sudden disability may have upon inter-familial processes. Certainly in the field of handicap generally, the disruption of normal family processes and functioning has been recognised, particularly with regard to handicapped children (17) and the mentally handicapped (18). Further, in the case of the parents of handicapped children, a variety of parental responses to disability in their children have been identified including shock, anger, guilt, grief and embarrassment (19). However, an argument similar to the one advanced earlier in the paper has been readvanced regarding the responses by the parents of handicapped children; there is a similar myth to the one concerning the psychological adjustment to disability and that is the myth concerning parental feelings of guilt, shame, etc., about their handicapped children (20).

Unfortunately, there has been little direct concern with the effect that disability might have upon a person's family, when that person becomes disabled suddenly and in adulthood. Specifically, with regard to spinal cord injury, the authors referred to earlier who put forward the developmental framework for adjustment to paraplegia (5) to consider the effects that sudden disability can have upon a family (21). Nonetheless, their consideration is solely geared to how a family can help the disabled person through the developmental stages of adjustment identified in this previous paper. Certainly there is no consideration of the fact that non-disabled family members (as significant others) can be actively involved in creating the meaning that disability will have not only for the disabled person, but for the whole family.

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While psychology has provided the theoretical framework for consideration of individual adjustment to disability, the major framework for consideration of the effects of disability upon family life has been derived from functionalist sociology, typified by Parsons and Fox (22) in their consideration of the effects of illness upon the urban American family. However, much of their argument is now out of date for they argue that the extra-familial care of the sick and disabled is functional to family life and stability since it removes potentially disruptive elements from the family situation. However, this argument was advanced before the ideological attachment and practical commitment to community care had taken hold in the 1960's and 1970's (23).

Interactionists have, by and large, not attempted to provide an alternative theoretical framework, but simply studied family processes at first hand. Thus a number of studies have discussed the role of other family members in creating, defining and treating behaviour that eventually comes to be recognised as mental illness (24). So, too, with physical illnesses, it has been shown that the meaning symptoms have for both sick individuals and other family members play a crucial part in determining when sick people eventually go to the doctor for a diagnosis (25). A recent study of patients presenting at a hospital for cataract surgery has shown that the crucial factor in the decision to operate was not the objective measurement of peripheral vision, but the perception of defective sight as a problem in living by the patient and his family (26). Within this tradition, a much neglected study of the wives of alcoholics has shown that their response was crucial in determining what subsequently happened to the family (27).

With regard to spinal cord injury (and perhaps disability generally) what is being suggested here is that adjustment to sudden traumatic disability is often harder for non-disabled members of a family than for the disabled person himself. A recent letter to the problems' page of a woman's magazine poignantly illustrates this point (28):-

> "My wife and I badly need help. Our only son has become paralysed and we simply cannot cope with this mentally although every practical help is being given to us. We thought of going to a marriage counsellor - but there is no marital problem as such. Far from it. We're devoted but very unhappy and unable to help each other."

It has already been suggested that one reason for this may be that the newly disabled paraplegic may be exposed to positive meanings associated with his disability whereas the rest of the family may not. Another reason may be that allowances are made and sympathy extended to the disabled person whereas other family members may simply be told to 'buck up as its not them that are paralysed.' Finally, in line with the psychological paradigm, most if not all of the support services will be concentrated on the disabled individual, his problems and needs, to the consequent neglect of other family members.

However, the point of this paper is not to provide an alternative interested explanation, but to provide a theoretical framework which may serve as a guide to further research. Hopefully, this framework may challenge and ultimately replace the psychological paradigm which has dominated research so far.

It certainly suggests that adjustment to sudden, traumatic disability must be conceptualised as more than just a problem of individual adaptation.

(d) Conclusion

Recently there has been revised political interest in the family as a social group. This paper has provided both a critique of the individualistic approach to disability and a theoretical framework which emphasises the importance of the family. The implications of this at a practical, policy level are that state and voluntary provision should be much more broadly based. It is not enough to aim at adjusting the individual to a virtually unchanged social environment, but rather that the meaning of disability must be changed, not just the disabled individual, but for society as a whole including non-disabled researchers, professional workers and other family members.

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ABSTRACT

Family life is contrasted before and after a serious road accident. The personal experiences of the author, her husband and baby daughter are described to illustrate the financial, physical and psychological barriers which arose. The financial barriers are the extra costs arising as a result of her being tetraplegic. The physical barriers are those ensuing from the requirements of caring for a disabled person 24 hours per day, 365 days per year for the whole of the forseeable future. The difficulties to be overcome to fulfil a useful purpose by lecturing on aspects of disability, being an active member of a Community Health Council and a Management Committee member of the Spinal Injuries Association are also quoted.

Aspects of psychological trauma are noted such as the readjustment of both patient and family to cope with all the difficulties of the new situation when the return from hospital to home takes place. Unless the husband or wife will overcome this barrier as did the author's husband, the disabled person must stay in hospital for the rest of her life. Despite all the barriers, survival as a family unit is possible as the author's 16 years at home illustrate.

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DISABILITY IN THE FAMILY

M. Winifred Howarth

Sixteen years ago I counted my blessings. I had three important things in my life. I was happily married, we had a daughter Anne who was 12 months old and I was enjoying my 22nd year in my nursing career. Family life was going along smoothly until one morning on the way to work I was innocently involved in a head-on car crash. This erected a whole series of barriers for myself and my family. As a result of the crash I became a tetraplegic due to severe spinal cord injury. I also suffered loss of my right elbow joint, petrol burns, and facial injuries. My tetraplegia means that I am paralysed from my neck downwards including a loss of sensation. I am incontinent of my bladder and my bowels. Some limited movement of my left arm remains. It is impossible to consider my life as a disabled person without relating it to my family. Immediately I became disabled the whole pattern, not only of my life, but also the lives of my husband and Anne were completely altered in three main aspects, financially, physically and psychologically.

To consider the financial barrier first. As soon as I became disabled our cost of living went up and our standard of living went down and has remained so. The compensation I was awarded, very small by todays standards, was indeed inadequate for our needs. A substantial part of it had to be used immediately in building a house suitable for my use in my new disabled state. The remaining money was invested in the hope that it might provide me a small income. In practice this proves negligible as the income is regarded as unearned income, and is added to my husband's salary and taxed at maximum rate without allowances. Despite building a labour-saving house we were no longer independent but had to employ domestic help. Financial considerations restricts such help to two half days per week. The result is that my husband is left, after doing a full time job - to cope with the rest of the housework, the washing, the cooking, the shopping etc. in addition to the usual chores of family life e.g. gardening etc.

Wear and tear on the house is greatly in excess of normal due to the necessity for nurses to come in and out at least twice per day and the wear to carpets etc. caused by my motorised wheelchair. From a health and comfort angle I need to maintain my rooms at 22°C which results in large fuel bills. Public transport is quite impossible for me to use. Unless therefore I am going to be a prisoner inside my four walls and not partake in family outings we must own a car. The recently available Mobility Allowance is of course a most welcome contribution towards the cost of this, but by no means covers all the expense of this essential item. Because my husband uses the car occasionally in connection with his work I am refused completely the remission of Road Fund Licence fee which is said to be granted to the disabled. For long distance travel the only satisfactory method is air travel which is of course very expensive indeed.

Telephone communication with the outside world is a necessity of my life and has to be carried out with the help of the special controls of the "Possum" unit for disabled people. I am charged extra for this special telephone.

After three years in the Spinal Injuries Unit of a hospital and several more years trying to establish ourselves as a domestic unit in our home we felt that we all really needed a holiday. However if it was to be any holiday for my husband we had to take a nurse with us in order to help to look after me along with himself and my daughter. We soon found that it is usually only the more expensive and larger hotels which have the facilities to accommodate a wheelchair e.g. lifts of adequate capacity etc. Thus instead of a holiday for three, it becomes an expensive holiday for four. My husband and daughter still have to assist in nursing me and looking after me, so they do not get the true holiday that I would like them to have. Because of my accident the cost of these things is far more of a burden to the family than it would have been had I continued as before. My occupation as a senior nursing officer commanded a good salary which would have enabled us to have family holidays without undue difficulty. As a severely disabled person it was considered impossible for me to return to my profession and earn the kind of salary I had formerly enjoyed. There is a continuous financial strain on the family as a whole. Furthermore as we grow older we must attempt to save for the time when retirement comes. I shall not have the retirement pension which would have followed my employment and our expenses may well increase as we need to employ extra help.

Clothing is now an even more expensive item than before. I cannot buy ready made clothing but need to have it made to measure. Also as it has to be pulled on and off me each day by other people, a process in which I am completely unable to assist, the rate of accidental damage to it is greatly increased.

It is clear therefore that the family faces considerable financial barriers when one of its members becomes disabled.

My severe physical disability means that I have to be washed, dressed and lifted each day into a wheelchair and vice versa. The physical work is also increased when I have to be transferred to a car by being lifted from my wheelchair by two persons into the front passenger seat. Despite present day mechanical aids we find there is no satisfactory alternative to the manual effort of two people when someone with my degree of disability is concerned.

The day to day duties are so continuous and demanding that my husband cannot stay in bed even if he is ill. Each morning it takes him at least one hour before he leaves for work and there are other duties which occupy him for a similar time in the evening.

From a very tender age my daughter had to help in the house, taking on responsibilities far earlier than can reasonably be expected of any child. By the time she was 7 years of age she was one of the two persons assisting in lifting me into a car. As a result of this she was deprived of the normal freedom to go out and play with friends of her own age and this loss of course is now irretrievable.

It has to be remembered that all these physical disabilities are present and have to be dealt with for 365 days every year. They are always present and of course unlike most illnesses they will not resolve one way or the other within any forseeable period. The work and extra attention continue for life.

There is of course a positive factor in the case of my daughter because as a result of the necessary duties she undertook she became independent at a very early age. Being cared for by a wide variety of people from elderly ladies to foreign young ladies with very different personalities she had to learn to cope with changes of all kinds.

I maintain a considerable interest in my profession as a nurse but the physical difficulty of even handling and reading the journals is formidable. Additionally I lecture on the nursing and other aspects of my disability to a wide variety of audiences. Having been elected to membership of public bodies where advice on nursing and all physical aspects of disabled living is needed, I make every effort to fulfil these commitments. However, the physical barriers are great. I have to be handed each book or paper to read. To handle a set of loose papers is impossible as I have no use in my fingers. I am only able to write a very few [illegible] with difficulty. Thus lecture notes, comment for meetings, [illegible] form of writing at length has to be undertaken for me by my fam[illegible] friends. To get to meetings or lectures involves two people to get [illegible] to a car, take me to the venue, get me out into my wheelchair, supply me with books and papers and repeat all of these things to return me to my home. I thus cannot accept an outdoor engagement unless I have the full assistance of two more people and this is a requirement which is very difficult to fulfil as often as I need it.

The fact that I have to be put to bed by two nurses or by two members of the family each night means that the family cannot lightly decide to have an evening out. In fact the physical barriers to it are so great that it is something which is rarely undertaken.

Mobility is indeed a matter of prime importance for the severely physically handicapped.

Psychological barriers also play a great part in the life of the disabled.

One of the first such incidents after my own accident was the occasion when my husband brought our daughter to see me in hospital. Some six weeks had already elapsed whilst the more obvious facets of my injuries were remedied. I had been looking forward to this moment but it proved a disaster. Anne at the age of about 1 year had changed physically in the time since my accident so that she appeared quite different to my memory of her. On her part she no longer recognised me with my very changed appearance and clamoured to go back to her father. Worse still, I had insufficient movement and power in my arms to hold her and I realised with horror that my loss of sensation prevented me completely from feeling her presence next to me. She had to go back to her father and I was left to come to terms with a very great deal of psychological trauma. A barrier had indeed come between me and my daughter.

Relatives and friends offered various solutions to the family difficulties such as that our daughter Anne should go to live with a relative in Australia or that she should go to a Dr. Barnado's home. This advice we rejected and despite the many difficulties that followed we decided then and would decide similarly again to try to remain as a family. The difficulties should not be underestimated when one remembers that I was in hospital in one town, our house was in another town some twelve or so miles away and my husband had a full time job in a third town about a similar distance from either. The trauma to both parents wondering how their young child was faring in the hands of a third person remote from either of them for much of the day was far from inconsiderable. The nursing staff on the Spinal Injuries Unit were unusually helpful in that they made the family unit welcome when they were able to be together for a short time at weekends. Their approach was very different from the strict visiting regimes imposed in many hospitals and contributed conspicuously to the welfare of the family and in helping to overcome psychological barriers.

There is a strong psychological barrier when a disabled person in a wheelchair is taken out in the community. The reaction of many people is well summed up in the title of the recent radio programme "Does he take sugar?" reflecting the assumption of the general public that someone in a wheelchair is of necessity unable to make even simple decisions for themselves.

It was psychologically traumatic for me when at the time when my daughter was only 7 years old, our domestic help left and my daughter had to be guided, verbally, in the preparation of simple meals. To sit helplessly while she tried to cook some food then had to serve it and cut it into small pieces for me to eat was not at all easy for me. I was at the same time anxious that she did not burn or otherwise hurt herself, yet as it was the only way we could manage I had to encourage her to proceed and conceal my fears for her safety.

Our daughter of course soon accepted the situation as normal and as a mere toddler would request nurses to attend to a blocked catheter or other necessary bodily function. Also although she and I suffered because of my inability to do anything about the lack of physical contact between us, there was a positive gain to her in the fact that I being relatively immobile had plenty of time to talk to her and listen to her whenever she so wished.

The enormity of the problem confronting a family when a severely disabled person is eventually discharged from hospital to home cannot be overestimated. Both sides have the most acute dread of the new situation. The patient realises that when home they will be separated from the 24 hour contact with experienced nurses and knowledgeable medical staff and all the supportive services. The knowledge of how much they depend on this teamwork - none of which will be available when they are home leads to irrepressable fears that it will be impossible to survive without these necessary adjuncts to their survival in their new handicapped situation. On the other hand the fears of the relatives about to be faced with the return of the disabled person are no less. They are appalled when they realise just how much attention and sheer physical work are required every single day. Morning, noon and night they will have to be present attending to essential needs of the disabled person. For the attendant as for the disabled person there is a similar loss of freedom. They can in future no longer go out for the day or the evening without giving it a second thought. They are unable to leave at all unless they can either persuade someone to replace them or to make the even more difficult necessary arrangements to take the disabled person with them. Adding to the dread of this enormous task which they are being required to take on, is the knowledge that it is not like a normal short illness which would be resolved one way or the other within a reasonable period of time. On the contrary it is a perpetual task for the whole of the forseeable future without remission. In the common case of the patient being a relatively young person and the relatives being parents the task is clearly one for the rest of the relatives life - a daunting prospect indeed. For example in the case of one young person who became disabled, when the time came for discharge from hospital no relative could be found, even though there were numerous close members of the family, who felt able to accept the burden of constant care of their disabled brethren. Whilst it is easy to criticize it is difficult for those not faced with such a prospect to comprehend the enormity of the fears and anguish of those placed in this situation.

The psychological barrier to accepting the new situation is indeed great. In many cases it leads to a complete breakup of the family owing to a breakup of the marriage under the stress of the new circumstances. In such a case the marriage vows of "for richer for poorer; for better for worse" turns out to be all for poorer and worse!

Experience amongst disabled people suggests that the temperament of the disabled person can make quite a difference to the acceptance of the new situation both by the patient and those who care for him. Patients who are extroverts appear to be able to adapt better and to engender better relations with their attendants than patients who are by nature introverts.

The patient also has to learn that for the rest of her life she will have to ask for assistance for everything no matter how small or large and to go on doing so repeatedly day in and day out. In order not to push the tolerance of attendants beyond the limits of endurance the patient must learn when to make requests, and when to stay silent and endure some kind of neglect in the interests of good relations. Inability of the patient to feel whether damage is occurring to the person leads to lots of requests for reassurance that all is well.

The question of asking for assistance has frequently to be learnt by the relatives as well as by the patient. The relatives will have to ask for assistance from nursing and medical staff on occasions. Also, and more frequently from either other relatives or from friends and neighbours in giving some assistance with the care of the disabled person. The request may be for someone to stay with the disabled person whilst a shopping expedition, a business trip, or a holiday is taken by the relative. It may merely be to assist in getting the disabled person into or out of a car or into or out of bed, but each time a request has to be made to someone. Only those with experience of this situation realise the psychological barrier that grows up within one and makes one dread the task of making yet another request for assistance. The knowledge that as with their situation, the request may well be a continually recurring one does not help. Even worse is the psychological damage when the answer to such request is a refusal without apparent good reason. This happens more often than many people care to admit. Following an accident in which one becomes disabled one finds an astonishing diminution in the number of friends who keep in contact and do not vanish from sight. A reduction of a circle of dozens of people to a mere handful is a common experience.

The foregoing will show that a whole series of problems and barriers beset a family of which a member becomes disabled but they have to be overcome and those who have done this must advise and encourage those still facing these obstacles.

MAJOR ADAPTATIONS AND HOW THEY CAN BE AVOIDED : PROFESSIONAL LIAISON BETWEEN ARCHITECTS AND OCCUPATIONAL THERAPISTS

Rosemary Barry*

ABSTRACT

A paper which presents the system operated in the Royal County of Berkshire for adapting property to the needs of handicapped people, and then examines the future in terms of design which takes account of disadvantaged people.

It discusses the need for an alteration in architectural norms and specifications so that major works of adaptation can be avoided. A number of practical suggestions are made.

"The worst sin towards our fellow creatures is not to hate them, but to be indifferent to them, that is the essence of inhumanity."

George Bernard Shaw (The Devils Disciple)

George Bernard Shaw wrote his play "The Devils Disciple" in the 1930's and in relation to the lives of handicapped and disadvantaged people in our community we have demonstrated the accuracy of his words. The subject of my paper today is an area of work where this indifference has been particularly noticeable.

It is a vast area requiring very detailed consideration, and in the time allotted to us I intend to concentrate on the ways in which the needs of disadvantaged people can be met and how they can be anticipated in the future.

To be realistic we need to examine and provide for these needs as they exist now and to learn from them to assist us to build more appropriately for the future. I am, therefore, going to describe the system of major adaptations operating in the County of Berkshire before attempting to discuss a more ideal situation.

In Berkshire, a major adaptation is an alteration or an addition to property inhabited by a disabled person, where the County Council's Social Services is making a contribution of £1,000 or more. £1,000 being the level at which all proposed works have to be submitted to the Social Services Committee for approval of expenditure.

The initial identification of need can come from a number of different sources - GP, District Nurse, Health Visitor, Hospital, Environmental Health Officer of the District Council, and often from the Occupational Therapist concerned with the case. After consultation with the Head Occupational Therapist and the client, the County Architect's Department is contacted for a joint visit to assess the possible solutions and provide sketch drawings.

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The Architect's Department is not able, at this point in time, to designate a particular member of staff to liaise with the Occupational Therapist, and thus on many occasions an architect will be assigned to the job who has no previous experience of the needs of the handicapped, and no special interest in designing for those needs. While this has disadvantages in terms of the development of specialist knowledge and the working relationship between two professionals, it does mean that a larger number of architects working for the County are involved in looking at and being made aware of the needs of handicapped people. They are also introduced to the way in which occupational therapists think in terms of meeting those needs - a way which is frequently much more basically functional than the aesthetic inclinations of an architect!

Another basic difficulty in the co-operative process between the two Departments is the difference of time scale. The County Architect's Department with its normal programme of long term contracts - schools, libraries etc., often find it hard to acknowledge and accommodate the urgency of many of the cases placed before them by the occupational therapists. In these days of stringent budget restrictions every available alternative to a major adaptation will have been explored in order to provide relief in a swifter manner and restrict the expenditure level to the minimum necessary. Most cases presented to the architects therefore need swift action.

A satisfactory solution is worked out in detail involving discussions between the client/architect/occupational therapist and head occupational therapist. The architect then produces the working drawings and specification, obtains the various planning and building permissions and invites tenders from three builders. The "satisfactory solution" is frequently a compromise between what the occupational therapist feels is ideal and what from the architects point of view is feasible given the limitations of the site - existing drainage, building regulations and so forth. The discussions include such aspects as the most suitable type of shower for the clients special needs, e.g. ability to transfer onto bench or the need for ramped access to shower, wheelchair space beside toilet for transfers, type of taps, height of windows etc. This type of discussion and compromise develops understanding of needs and professional respect between the two disciplines, and we have experienced some excellent support and co-operation. In the case of private property the County Architect also supplies the County Property Officer with a copy of the Plans so that he, together with the County Secretary, can establish, where appropriate, a level of charge on the property, and place this with the house Deeds. This charge is equal to the increased value of the property subsequent to the adaptation, and is repayable on an interest free basis if the property is sold.

After the Committee agrees the expenditure, the County Architect, with the Clerk of Works, runs the contract, while the occupational therapist keeps in constant touch to ensure that particular items are as specified - height and position of toilet, rails etc., and also to provide the support and encouragement that is so often needed by the client and their family who seldom seem to have appreciated that having the builders on site could be quite such a messy business!

The type of adaptation most frequently required is a bedroom/shower/toilet extension. Alternative toilet/bathing facilities are next in frequency. These adaptations seem to cost between £4,000 - £6,000 and the Architect, the Occupational Therapist and the Quantity Surveyor have to work closely to ensure that the essential elements are retained in any scheme while "frills" are dispensed with, so that the already inadequate financial provision can be stretched to provide assistance to the maximum number of clients. Most adaptations appear to take at least twelve months from the time of referral to completion.

The cost, time and inconvenience of these procedures leads us to consider how the needs of handicapped people can be anticipated in the future. The Occupational Therapist, and in particular those working in the domiciliary field spend a substantial portion of their working lives looking at the problems of ADL - Activities of Daily Living. These problems are always handicapped-related, but frequently the environment is the cause of the greatest handicap. Steps, stairs, toilets, bath, door widths, passage widths, are but a few of the environmental handicaps. Local Authorities through the Chronically Sick and Disabled Persons Act, are empowered to provide such aids and adaptations as are necessary to enable the disabled person to remain within their own home in "greater safety, comfort and convenience". Many of these adaptations would be unnecessary if their home had been built with a disabled person in mind. While I appreciate that the older houses were built before the needs of handicapped people were acknowledged, we should now be building houses which do not need substantial alteration to accommodate a handicapped person. Regrettably this is not the case.

It should be remembered that at least 70% of the population will be disabled in some way during their lives - either temporarily or permanently - and that the likelihood increases for each individual with advancing years. True one need not consider Anno Domini as a disability, but its effects in terms of practical living can be disabling. Yet we continue to use the same specifications for building homes as we do for building an Olympic village.

Mobility housing standards are probably the most significant advance in terms of catering for future known and unknown needs. It is distressing that this attracts only a £60 grant per unit towards "extra cost". We need to turn our priorities upside down so that mobility housing becomes a universal standard thus allowing total integration. Mobility housing does not inconvenience an able bodied person but the reverse is not true.

Specialist housing/wheelchair housing should, in fact, be mobility housing with a possible increase of circulation space and a greater degree of flexibility of use. Certain specialist provision for wheelchair users can be made in terms of a split level cooker, shower unit, wheelchair space beside the toilet and height of windows, but other facilities will need to be adjusted for the individual in any case. All disabled people are individuals and one wheelchair user will have different needs, likes and abilities from the next. Work surfaces and cupboards on a ratchet system will allow these variations to be accommodated quickly and with minimal expense. Sinks with variable height positions, strengthened beams in all rooms where a hoist might be needed will allow for alteration of room use. Kitchens are frequently the most carefully and specially adapted areas, and equally frequently the disabled person is not the one doing the cooking.

All houses built with disabled occupants in mind should incorporate certain standard features; toilet height not less than 18" with the pan projecting forwards sufficiently to allow for the seat of a wheelchair to be level with the toilet seat for side transfer. Frequently insufficient space is left to accommodate the back wheels of a chair, with the result that the person transfers onto the front of the toilet seat. Baths should be at least six inches off the floor, as this allows the side panel to be cut to enable the legs of a hoist to go underneath the bath. Unfortunately, the modern type of fibreglass bath does not make the fitting of bath aids easy because their sides are flexible. Incorporation of a shower trap during construction allows baths and showers to be alternated to suit individual need. Pipes in the floor of the bathroom need to be sited away from the rear of the bath where an auto lift might be fitted. Throughout the house window catches should be at a low level and easily operated, and the lower sills mean that someone seated in a chair can get a reasonable view of the outside world. This is, in fact, true for able bodied as well as disabled people - particularly children - and where handicapped children are concerned, it enables the mother to keep an eye on where her child is and what he or she is doing without having to go constantly to the window to look. This is especially relevant where a mentally handicapped child is concerned. Straight staircases are obviously preferable, not only because they make the fitting of a stairlift much easier, but also for elderly and ambulant disabled, including the blind and partially sighted, the triangular step that frequently goes with the curved staircase is a potential hazard. However, even with the straight staircases, construction of the stair wall needs to be sufficiently solid that it can take a wheelchair platform wall mounted stairlift. There is also a problem within some modern flats as walls are constructed of a plasterboard skin with cellular cardboard in between. Not only does this not take a stairlift, it will not even support the fixing of a handrail.

Rampable access to at least one door is a necessity but it needs to give access to both pavement and garden. Showers are a facility about which occupational therapists have a certain amount of knowledge and expertise. There are a number on the market meeting different needs and where construction of a shower unit for a particular person is being considered it is important that the Architect liaises with the occupational therapist on the client's particular needs. As already mentioned in some cases to have a shower tray can be a distinct disadvantage and the shower is best sloped towards the drain so the chair can be used. For other clients who can transfer, the normal shower tray with bench or stool may be sufficient. There is always the problem too, that if the person is going to have assistance while showering, particularly from a district nurse, one has to try and provide a layout whereby the helper is not obliged to take a shower as well. The provision of a shower unit in an accessible place within sheltered accommodation units, old people's day centres and day centres for handicapped people will often obviate the need for individual showers to be fitted and provide a bathing facility to a large number of people.

The advent of the through lounge/diner has presented another set of problems. Frequently this and the kitchen are the only rooms downstairs and there is nowhere to place a bed and/or commode, even on a temporary basis. The provision for the possible addition of a partition, i.e.

fixing points would quite often solve the problem with minimal delay and expense. So often the time factor is the greatest problem as any construction work, major or minor, is a time consuming occurrence.

Many of these points are not included in dwellings at the present time, for no better reason than the Architect was not aware of the need for them. Liaison between Occupational Therapist and Architect can soon remedy that.

Siting of "specialist" units is important - in one town I know, the old people's home is placed in a magnificent site with a commanding view of the countryside and town. It has one major drawback: it is on top of a 1 in 7 hill. As a result the participation in the town's events and facilities by the old folk is very limited, and even the passing pedestrian traffic is both infrequent and slow! Similarly, to site wheelchair flats or bungalows amongst non-mobility standard housing is preventing disabled people from much normal social integration as so frequently they have to play host since they cannot be accommodated in friends and neighbours homes. It also often prevents them from "doing their bit" as many would wish to do in appreciation of assistance given - baby sitting, sick visiting etc.

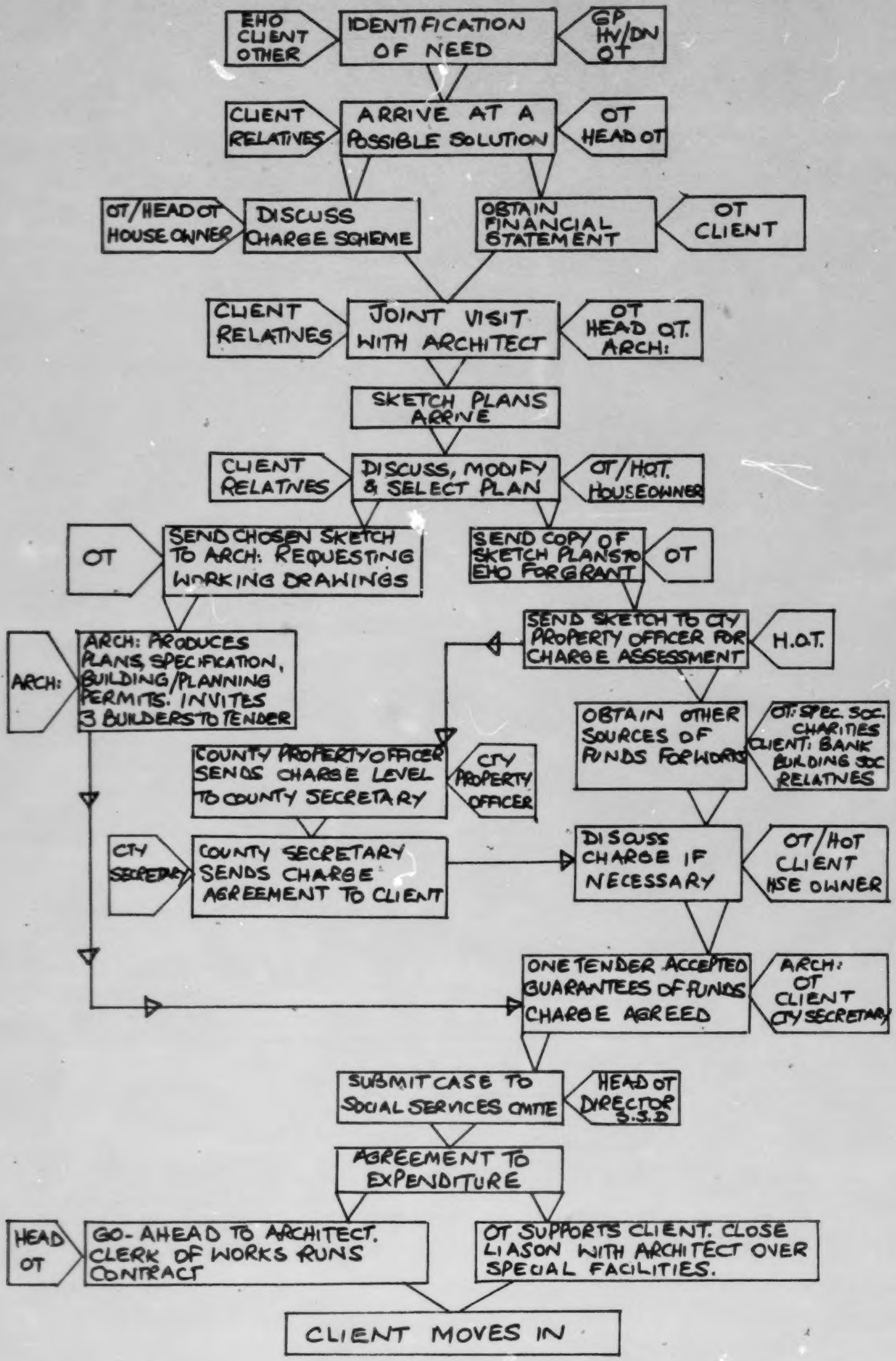
Access is so often the main barrier between the disabled person and the more normal existence - kerbs, steps, including bus and train steps - doors, stairs, and toilets - particularly public ones - why have special loos which are kept locked? - If all loos had one wheelchair cubicle then the problem would not arise. Disabled people have difficulties in using many facilities that the able-bodied take for granted. With a bit of careful thought and planning by Architects and Town Planners these difficulties could be largely eradicated. The installation of the induction loop system for the deaf into a new theatre or concert hall will immediately open a new door for the many deaf and hard of hearing in our population. Facilities for the use of a hoist at a public pool allows many disabled swimmers the opportunity to join in that sport. Often a major barrier to the employment of handicapped people is the employment environment - not the individual's ability to work. The list is endless.

Occupational Therapists meet and deal with problems of this kind with monotonous regularity. Substantial amounts of money are being spent annually on circumventing them. Such problems need never occur with careful planning, thus releasing this money to be spent more profitably on enhancing the quality of people's lives, as opposed to assisting them to exist. I must repeat what I have already said - facilities for the disabled do not inconvenience the able-bodied while facilities for the able-bodied most definitely do disadvantage the disabled. Only by acknowledging that there are substantial numbers of disabled and elderly people in our community, and by becoming aware of their needs as human beings, will we start to build an environment which does not disadvantage certain sections of people.

Architects play a major role in the development of our environment, and Occupational Therapists play a major role in dealing with the problems and hardships experienced by the handicapped people as a result of those developments. We need to foster a close liaison between the two professions, and increase the knowledge of each others expertise. Architectural training should contain more about the designing needs of the disabled and about the various professions associated with disabled people, and Occupational Therapists need to be made more aware of architectural factors involved in providing for handicapped people, so as to make realistic demands on architects.

I am certain that the close working of these two professions can go a long way in ensuring that the world we are building for the future can be enjoyed by all who live in it - thus giving the lie to George Bernard Shaw.

MAJOR ADAPTATIONS PROCEDURES: PRIVATE PROPERTY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GP HV/DN OT
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ARRIVE AT A POSSIBLE SOLUTION
OT HEAD OT
OT/HEAD OT HOUSE OWNER
DISCUSS CHARGE SCHEME
OBTAIN FINANCIAL STATEMENT
OT CLIENT
CLIENT RELATIVES
JOINT VISIT WITH ARCHITECT
OT HEAD O.T. ARCH:
SKETCH PLANS ARRIVE
CLIENT RELATIVES
DISCUSS, MODIFY & SELECT PLAN
OT/H.O.T. HOUSEOWNER
OT
SEND CHOSEN SKETCH TO ARCH: REQUESTING WORKING DRAWINGS
SEND COPY OF SKETCH PLANS TO EHO FOR GRANT
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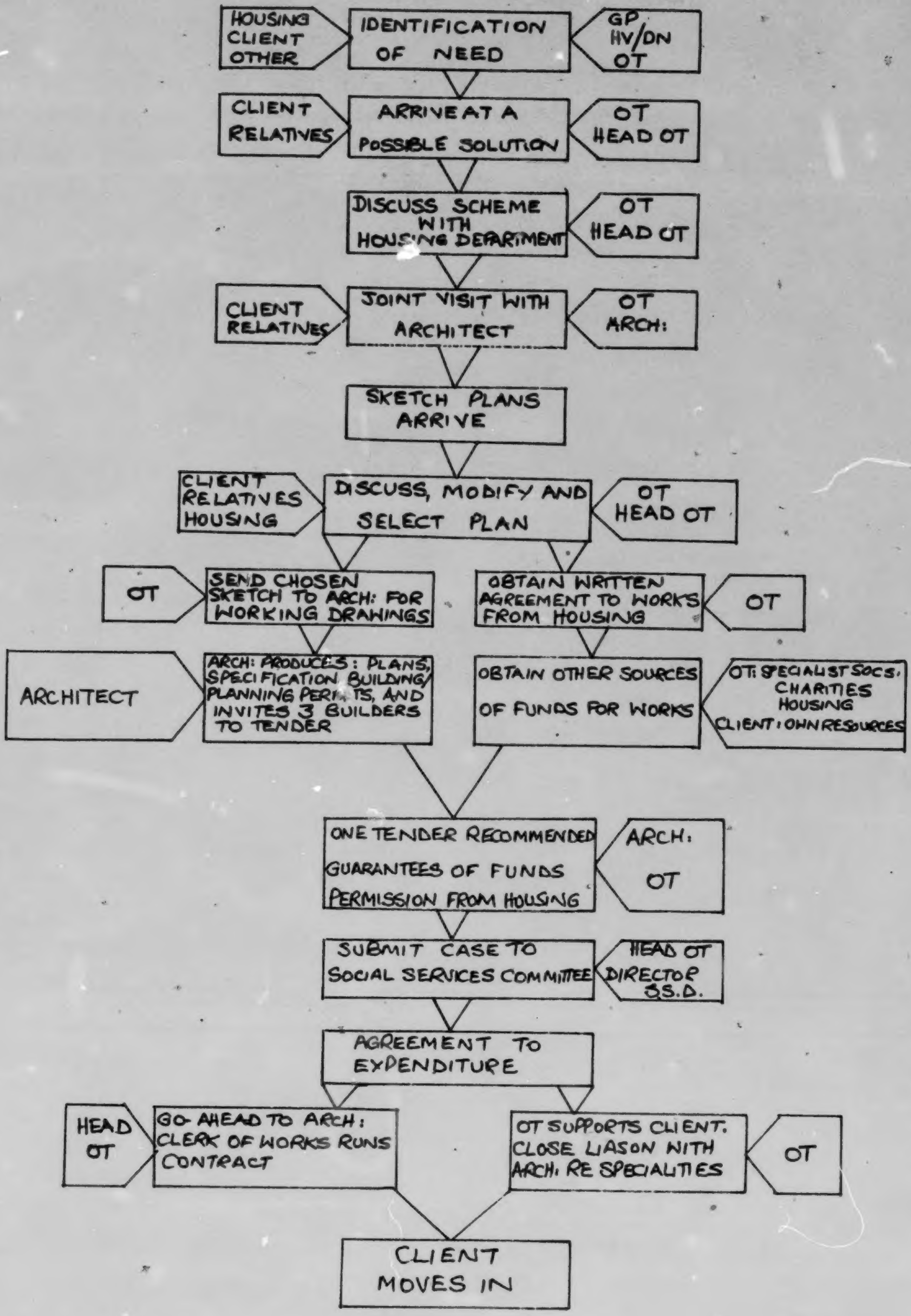
ARCH: PRODUCES PLANS, SPECIFICATION, BUILDING/PLANNING PERMITS: INVITES 3 BUILDERS TO TENDER
SEND SKETCH TO CTY PROPERTY OFFICER FOR CHARGE ASSESSMENT
H.O.T.
COUNTY PROPERTY OFFICER SENDS CHARGE LEVEL TO COUNTY SECRETARY
CTY PROPERTY OFFICER
OBTAIN OTHER SOURCES OF FUNDS FOR WORKS
OT: SPEC. SOC. CHARITIES CLIENT: BANK BUILDING SOC RELATIVES
CTY SECRETARY
COUNTY SECRETARY SENDS CHARGE AGREEMENT TO CLIENT
DISCUSS CHARGE IF NECESSARY
OT/HOT CLIENT HSE OWNER
ONE TENDER ACCEPTED GUARANTEES OF FUNDS CHARGE AGREED
ARCH: OT CLIENT CTY SECRETARY
SUBMIT CASE TO SOCIAL SERVICES CMTTE
HEAD OT DIRECTOR S.S.D
AGREEMENT TO EXPENDITURE
HEAD OT
GO-AHEAD TO ARCHITECT. CLERK OF WORKS RUNS CONTRACT
OT SUPPORTS CLIENT. CLOSE LIASON WITH ARCHITECT OVER SPECIAL FACILITIES.
CLIENT MOVES IN

MAJOR ADAPTATIONS PROCEDURES : PUBLIC SECTOR


HOUSING CLIENT OTHER
IDENTIFICATION OF NEED
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OBTAIN OTHER SOURCES OF FUNDS FOR WORKS
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ONE TENDER RECOMMENDED GUARANTEES OF FUNDS PERMISSION FROM HOUSING
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HEAD OT DIRECTOR S.S.D.
AGREEMENT TO EXPENDITURE
HEAD OT
GO-AHEAD TO ARCH: CLERK OF WORKS RUNS CONTRACT
OT SUPPORTS CLIENT. CLOSE LIASON WITH ARCH: RE SPECIALITIES
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CLIENT MOVES IN

A COMMUNITY OCCUPATIONAL THERAPY SERVICE

Author: Jean Higgins

THE ABSTRACT

This paper will give a brief historical outline of the formation and development of the first Community Occupational Therapy Service in this country which Surrey started in 1936. It highlights the aims of the Service, the occupational therapists role within the team, the staffing structure and short job descriptions, transport arrangements for both staff and clients, the rehabilitation needs of the clients in the 3 main aspects of life (1) physical, (2) psychological and social, (3) economic including the sale of craftwork and a final summary showing the challenge for the future.

I am very pleased to have been asked to speak to you about the first Community Occupational Therapy Service started in this country in 1936 and the developments which have taken place over the years since the inception.

BRIEF HISTORICAL OUTLINE

In Surrey Occupational Therapy was first started in 1936 by a voluntary organisation for the homebound tubercular patient and the value of this service was soon recognised so administration was transferred to the Local Authority Health Service in 1938. In the early 1950s with the control of tuberculosis the service was extended to include "other chest conditions" and in 1959 the "scheme for the provision of Welfare Services for Handicapped Persons" was adopted, and the Occupational Therapy Service dealt with anyone who was substantially and permanently handicapped. In 1966 a pilot scheme for the elderly was launched and the same year partial integration of the services for the blind with further integration in 1967.

As well as these developments to provide a comprehensive Community Occupational Therapy Service, there was also internal replanning in local government, which included the amalgamation of the Health and Welfare Departments into one common department, followed by two other changes:-

1. The Local Authority Social Services Act 1970, and
2. Chronically Sick and Disabled Persons Act 1970.

The introduction of these Acts meant tremendous reorganisation within Authorities, many of whom had no Community Occupational Therapy Service. Now I am pleased to say Local Authorities are aware of the value of Occupational Therapy and acknowledge that the concept of a Community Service is a very logical one because so much of an Occupational Therapist's work is concentrated on the achievements of normality, whether it is personal independence, behaviour patterns, social skills or preparation for work.

AIMS OF COMMUNITY OCCUPATIONAL THERAPY

I can do no better than quote from the leaflet of the British Association of Occupational Therapists "To develop, restore to, or maintain a client in his normal place within the community enjoying the maximum independence in the physical, psychological, social and economic aspects of life".

Any therapy aimed at independence is best carried out in the person's normal home environment rather than in the artificial setting of a hospital which tends to foster dependency and pre-occupation with ill health. However hospitals have an extremely important role to play and close co-operation must be maintained with hospital colleagues. On the client's discharge from hospital the Local Authority has a great responsibility and should give constant support, if required, to maintain the level of rehabilitation achieved in hospital and progress further in the home situation.

Broadly speaking the national policy is for a client to remain in the Community as long as possible and return to the Community as soon as possible.

THE OCCUPATIONAL THERAPIST'S ROLE WITHIN THE TEAM

Whilst Occupational Therapists have an important contribution to make in the resettlement of a disabled person, we must stress contribution because they are members of a team who together should provide a fully comprehensive service for the handicapped person in question. Occupational Therapy is a specialist service within a local authority which should not operate in isolation but in co-operation with all other services.

It is difficult to define the word "team" because there are so many people, both professional and lay, making a valuable contribution, eg. family doctor, district nurse, social worker, home help, architect, housing manager, voluntary visitor, etc., but it must always be remembered that the first and most important person is obviously the handicapped person who must play as active a part as he or she is able in any discussions and decisions. The degree of involvement will, of course, differ from client to client. In all cases the family will also have an important role to play and will contribute to the total team effort to, where possible, maintain the client within the community.

So often the Occupational Therapist finds one of the most important factors is to re-educate and retrain the family as well as the disabled person, because they can easily become over-protective. If the home can be re-arranged to enable the disabled person to function independently it will not only benefit the relations but also the disabled person, overcoming frustration, tension and generally improving the morale of the family.

The skills of the Social Worker and the Occupational Therapist, who by training, is medically orientated, complement each other, but it is the Occupational Therapist who provides the essential insight into the manner in which a handicapped person copes with day to day activities and knows ways of overcoming their difficulties. With her medical knowledge, she is able to take into account the diagnosis, age, prognosis, psychological adjustment to disability, involvement of the family and relations and many other factors to enable her to make the correct assessment.

STAFFING STRUCTURE WITHIN THE OCCUPATIONAL THERAPY SERVICE

Over the years we have found it advisable to build up the service from an initial tier of Occupational Therapists who then should have good supportive sections, eg. technical, craft instructors, supplies and marketing, administration and clerical. This forms a completely integrated staff within the service and allows the Occupational Therapist to perform the professional role for which he/she is trained, under the guidance of a Head Occupational Therapist who is based at the main Rehabilitation Centre.

PATTERN OF STAFFING

Head Occupational Therapist responsible for:-

(1) The Community Occupational Therapists with the County.
(2) Advise on suitable activities for clients' in the Day Centres for Physically Handicapped.
(3) Authorisation of aids, equipment and minor adaptations over £25.
(4) Support for the Senior Technical Instructors in progessional aspects relating to aids, equipment and minor adaptations.
(5) Lecturing to many groups of people, eg. Schools of Occupational Therapy, Social Workers, District Nurses, Health Visitors, etc.

Occupational Therapy Training Officer

Responsible for:-

(1) Occupational Therapy Students who are placed within our Service during their clinical practise.
(2) Training volunteers in craftwork throughout the County who will work with the physically handicapped, blind, mentally ill and elderly in Day Centres, Classes, Residential Homes, etc.
(3) Arranging regular meetings of all Community Occupational Therapy staff and recording the minutes of same.
(4) Giving talks to voluntary or statutory groups about the Occupational Therapy Service.
(5) Acting as relief Community Occupational Therapist within the County.

Assessment Officer (A qualified male Occupational Therapist)

Responsible for all special assessments including overhead tracking and hoists, stair-lifts and the more complicated major adaptations, in conjunction with a County Architect who specialises in the physically handicapped.

Administrative Officer

Responsible for all the ordering, controlling stocks, accounts and disposal of craftwork made by clients throughout the County. Also the clerical staff attached to the main Rehabilitation Centre.

Community Occupational Therapy Teams

Surrey is divided into 3 Divisions and 11 Social Work Districts. In each of the 3 Divisions there is a Day Centre for the physically handicapped which includes (a) a complete assessment flat; (b) aids display and demonstration room; (c) stores of aids, equipment and craftwork. These Centres are the base for the community teams which operate in each of the 11 Districts.

The 11 teams each consists of:-

(1) An occupational therapist who is the team leader.

(2) A technician.

(3) A craft instructor.

Occupational Therapist (Team Leader)

(1) The assessment, provision and instruction of aids to daily living and minor adaptations.

(2) Reports on major adaptations in conjunction with the Head Occupational Therapist, Assessment Officer and Architect.

(3) Recommendation and provision of suitable occupation for domiciliary clients.

(4) Rehabilitation and re-training required within the home situation for the physically handicapped clients and carefully selected psychiatric clients.

(5) Assessment of physically handicapped clients for Day Centre attendance.

(6) Consultative role in the Day Centres.

(7) Liaison with Hospital Occupational Therapy Departments within her District, including visiting patients before they are discharged home.

(8) Liaison with District Social Workers being in close touch with their District Social Work Office.

(9) Regular visiting of Residential Homes for the Elderly to advise the staff and residents on any problems of daily living.

Technicians

The Technicians design, construct and fix aids and minor adaptations which have been assessed by the Community Occupational Therapist, using their individual trade experiences and skills. The Technician also advises the Occupational Therapist on any technical aspects which she may require to know.

Craft Instructors

These Instructors work both in the domiciliary field with the physically handicapped and blind, and in the Residential Homes for the Elderly, in all cases providing suitable occupations under the supervision of the Occupational Therapist.

Administrative and Clerical

In the 3 Day Centres there is full administrative and clerical staff for the Community Occupational Therapy teams to provide them with support of a non-professional or technical nature.

TRANSPORT

In any community service good transport is essential. This is divided into 2 main areas:-

(1) Staff The type of vehicle, whether owned by the County Council or by the individual staff member, must be suitable. In Surrey there is a wide variety of vehicles, saloon cars, estate cars, vans from minis to 1½ ton.

(2) Clients Whilst every effort is made to encourage the use of public transport there is inevitably a large proportion for whom a service must be provided, especially to enable the physically handicapped to attend a Day Centre. In Surrey we have a fleet of 20 multi-purpose Ambulances attached to the Social Service Department under the control of a Transport Liaison Officer. These vehicles are specially designed and will transport a maximum of 9 seated clients, 6 wheelchair clients or a combination of both. When not in use for this purpose the Senior Practical Assistants, who are employed to drive the vehicles, deliver and collect aids, equipment or industrial work, as well as assisting in the Day Centres, therefore both the staff and the vehicles are used to their maximum capacity.

REHABILITATION OF THE CLIENT

These are divided into two main groups:-

(1) Ex-hospital clients.

(2) Clients not having contact with hospital.

Group 1 In this group, the ex-hospital client, it is essential to have good liaison between hospital and community occupational therapists, with complete co-operation. Both have much to offer for the benefit of the client, who is their joint concern. Visits of community occupational therapists to clients in hospital should be encouraged, just as joint visits to client's house can be most valuable to the hospital occupational therapist.

Group 2 The client not having contact with any hospital, when it must be realised that if a substantially and permanently handicapped person is referred to our service he/she is with us for life.

One of the most distressing aspects of physical disability is a lack of physical independence in the normal Activities of Daily Life. To the handicapped person dressing and feeding can be a formidable task. The aim of the Occupational Therapist is to teach the patient to establish and maintain the highest level of independence possible in the face of his impairment.

The important point to remember is that rehabilitation is not static, but active, on-going and contributory and that the "whole" person must be treated. Rehabilitation is therefore a challenge, and the Occupational Therapist aims at restoring or maintaining the patient to his normal place within the Community, enjoying the maximum independence in 3 aspects of life:-

(1) Physical

(2) Psychological and Social

(3) Economic

Physical Aspects

These are any therapeutic measures such as:-

(a) Assessment of needs

(b) Supply of aids and equipment if necessary

(c) Re-training either in one of our Assessment Flats, and/or in the client's home.

In 1977, Occupational Therapists made 14,061 domiciliary assessments, compared with 5,221 in 1972. £63,373 was spent in 1977 on aids, equipment and minor adaptations compared with £30,857 in 1972.

In every case aids must be purposeful - NOT act as a prop or to be supplied to replace a function which could be carried out naturally by re-training. This means the difference between guesswork and professional assessment, the difference between a client wanting an aid and needing an aid. Many aids are specially designed and made by Technicians for individual client needs.

Psychological Aspect

The provision of some activity, usually started within the home, which should be planned to meet the individual needs of the client, it often has to overcome the stress and strain within the home which has been produced by prolonged disability. It may be necessary to introduce an activity which acts as a stimulant in some, sedative in another, and is often a forerunner to future activities. The form of activity must be in keeping with the disability, create an interest and be progressive in nature. It could be Craftwork (in 1977 £21,205 was spent on materials) and may be the start of remunerative occupations, (Bentalls, Harveys etc) commercial subjects, art or music, all these are suitable provided they are purposeful and they help the patient to live with his disability.

Disposal of goods made is essential and we have no problem over this. The County Council have a Sales Caravan which was given by a Voluntary Association in 1958 and has proved invaluable. (Shows, fetes, factories). Apart from this particular sales outlet, clients are encouraged to sell their own goods (maintenance of independence).

When the need, and indeed the personal desire, for outside contact becomes apparent, arrangements are made for the handicapped person to attend one of the Day Centres within the County, for which transport is available. Attendance not only assists the client to re-adjust himself to community life and to take part in social activities, but it also relieves the relatives of their responsibility for at least a short period.

Economic Aspect

Progressive development, continued observations and assessments, the interest and economic needs of the client are all factors in the provision of the next step which is remunerative occupations. There are several reasons for progression, but mainly it is a step towards normality, a challenge to the patient, stimulation to achieve something which they have lost, and it creates a spirit of independence through earning even a small amount and contributing towards the family needs.

This may include printing, chair-caning, making or refurbishing aids, or light industrial assembly work.

SUMMING UP

The role of the Occupational Therapist in the community is to assess the continuing practical needs of the client physically, psychologically, socially and economically and take the necessary action in order that he/she, within the limitations, may have as normal a place and play as active a part as possible within the Community.

The Occupational Therapy teams as a whole, and the staff individually, have an exciting and challenging role to play - full of promise, yet alive with problems, but satisfying to the extreme.

Finally, I make no apology for quoting a paragraph from the Piercy Report which was written in 1959 but is still just as relevant today and on which we have built our Community Occupational Therapy Service.

> "The handicapped person should be enabled not just to live in the community, but be able to contribute to it by work, if that be possible, and by playing a part in whatever social life exists around him. In particular his self confidence and self respect must be returned or developed. One of the most valuable services that can be rendered to him is to implant in him a feeling that he matters, and that his well being is of concern to the community".

References:-

(1) British Association of Occupational Therapists Leaflet "Occupational Therapy Service in the Community".

(2) The Piercy Report 1959 "The Rehabilitation, Training and Resettlement of Disabled Persons". HMSO.

Seminar 3

Organised by the Royal National Institute for the Blind

BLINDNESS

Chairman: *Dr. Jan Huyers*

Advice to the Newly Blind
Mr. Bengt Hoflin

The Visually Handicapped Family and the Environment
Mr. Svend Jensen

Specialised Services for the Blind
Mr. J. E. Venn

Rehabilitation of the Multiple-Handicapped Blind
Rev. Coote

FREE PAPERS

Chairman: *Mr. J. M. Blackwell*

Developing of Independent Daily Living Skills and the General Maturing of the Severely Handicapped Teenager
Mrs. Barbara Newman/Miss Jill Vernon

ADVICE TO THE NEWLY BLINDED AND THE FAMILY

Bengt Hoflin and Ingrid Hoflin

A person becomes blind or partially-sighted but must learn how to live as a visually handicapped person. To adapt to the change in their life when such an important sense as sight is no longer functional can be a very difficult adjustment to make, although it is not the same for all.

One factor which is of significance for how an individual will adapt himself to the changed situation is the individual's age when the visual impairment occurs. To become visually handicapped means, to a very great extent, to relearn a new pattern of acting and reacting.

Earlier experiences are another important factor with respect to how an individual will be able to adapt to his changed situation. A further also very important aspect is family relationships.

In Sweden we use "visually handicapped" to describe people whose sight is so impaired as to affect their way of life. A visually handicapped person, can be completely without sight, i.e. be blind, can see sufficiently so as to be mobile but cannot discriminate details, i.e. severely visually impaired, or can have as much sight so that both mobility and reading of large print, with or without optical aids, is possible, i.e. partially-sighted.

The experience of one's self is another important factor in the changed situation. Every culture has its stereotype of a person who is "normal". Every culture also has its own idea of how a blind person should be and, about what possibilities there are for a blind person to function together with others. This is also felt by those who themselves become blind, but at the same time they have their own self-concept from their earlier experiences of themselves and their life.

The concept of a partially-sighted person is more diffuse, since partially-sighted persons can sometimes be taken for sighted persons and at other times as blind persons. It is not so easy either for the partially-sighted to describe in words what they see. It changes from situation to situation. It can be rather trying to be constantly reminded of one's handicap through misunderstandings from those around one. Furthermore the partially-sighted also have their self-concept from their earlier experiences of life as fully sighted persons.

According to Erving Goffman, professor in sociology and anthropology at the University of Pennsylvania, the physical, psychical and social "deviant" are labeled as exceptional by the "normal". They become stigmatized. That difficulties come with a sudden stigmatization depend, according to Goffman, on that the individual knows all too well what he has become. The stigmatized are thrust constantly into the problem of how he should meet society's stereotyped demands and expectations: Should he openly confess his stigma and perhaps risk putting off many people that he comes in contact with, or should he do everything possible to conceal the stigma, at any cost strive after adjustment to the "normal" society?

The individual's experiences from his upbringing are important. Artist, sociologist and psycho-analyst Erik Homburger Erikson devides in his book Childhood and Society people's development into maturity stages, which follow one another in a certain order. In each stage the organism must adapt itself to both outer and inner relationships and each stage dominates a certain time of the individual's life. That which happens during a particular phase affects also how development continues and influences the individual's future interpretations of his earlier life.

Every period has its psycho-social crisis, which arise because the biological development produces new behaviour in the child, to which those around him react. The interplay between the child and those around him culminates in a crisis. The solving of the crisis is of vital importance for the child's future reactions and experiences. The solving of the different crisis is according to Erikson decisive for the individual's ability to form an identity.

Identity formation is also developed through the child "identifying" with significant people in his environment. When the identity formation reaches its culmination during puberty, the crisis result in the individual either finding himself, his identity, or experiencing a lasting splitting of roles.

A feeling of an optimal identity is experienced as a feeling of psycho-social well-being, One feels at home in one's body, thinks that one knows what one is doing and is secure in the thought that one is accepted by persons who mean something. The identity is a synthesis between the identities the individual has experienced during the different stages of maturity and the roles the young person has tested during his "hunt" for identity.

When a visual impairment occurs, this can mean a so-called traumatic crisis for the individual. The consequences of the crisis reaction is dependent on the strength of the visually handicapped person's identity, the reactions of those around him, how the individual believes that he, in the future, will be able to fulfil those roles which, for the individual, are the most significant in his existance and on the individual's earlier attitudes towards blind persons.

Traumatic crisis are divided into different phases. Thus, for example, the psychiatrist and psycho-analyst Johan Cullberg in his book Crisis and Development divided the traumatic crisis into four different phases.

The first phase, the shockphase,can, for those who become suddenly visually impaired, mean that the individual's ability to function normally is put out of order. He can, for example, become unable to comprehend and remember information from his surroundings. The shock phase is usually very short-lived.

After the shock phase comes the reaction phase, which includes the mourning reaction, when the visually handicapped person mourns his sighted self which has died. During the third phase - rebuilding - the visually handicapped person and those sighted people around him become adapted to each other.

One usually distinguishes between three different types of adjustment. "Inner adjustment" can be defined as "an harmonious balance between instinctive and emotional needs, self-activities and the individual"s moral- and self-ideal". An "outer adjustment" can, according to one viewpoint, occur in three different ways: "One submits to the goals and demands of those around one,

one co-operates actively with those around one in order to bring about a change, or one chooses a new environment which suits one's own way of functioning".

The individual is "technologically adjusted" if he has learned, in his day-to-day life, how to compensate for his visual impairment through different techniques and sensory aids. He has made new habits for himself through training.

One also talks about visually handicapped persons accepting their handicap. This implies an inner adjustment. The individual realises that he has a handicap but doesn't underestimate himself because of it. He has made it clear for himself what possibilities remain for him. Those who have accepted their handicap have then come into the fourth phase - re-orientation - in which the individual incorporates those experiences he has had as a result of the impairment with his earlier experiences of life.

Another significant factor is the visually handicapped person's immediate environment - his family. It has been found that the other members of the family usually react by being either overprotective or worried. That some people overprotect can depend on feelings of guilt or ideas about their own superiority and significance. Those who become upset underestimate the visually handicapped person as well as themselves. As a consequence of visually handicapped people often being the only one in the family who is visually impaired, it is easy for them to experience a feeling of being an outsider,they differ in an obvious way from the other family members.

Psychologist Kajsa Dellgren has carried out an investigation of the situation of 86 visually handicapped people who received help in rehabilitation provided by the community. A dominating goal for the investigation was to increase knowledge of a completely general nature, about the whole process of rehabilitating a visually handicapped person. Thereby, it should become possible to trace possible short-comings in the system. It should mean new possibilities for improving the planning and contents of the rehabilitation courses as well as aptitude tests and occupational advice and education.

Kajsa Dellgren means that the individual's most powerful experiences, with respect to either pleasure or discomfort, is concentrated on those areas of life which he experiences as the most important. Experience within these areas then gives colour to the other areas. Thus, life can be experienced as meaningful by the individual either by getting satisfaction in life through his occupation, through his family life, through social activities and relationships or through hobbies and intellectual interests. Kajsa Dellgren has in this way formulated the general psychological criterion for rehabilitation: A person is rehabilitated if he himself feels that he is living a meaningful life.

To the question of what the visually handicapped thought was the most difficult to get used to after the onset of the visual impairment, most of both blind and partially-sighted, answered, "the restrictions on mobility". In the intermediate group - the severely visually impaired - inability to read is most often mentioned, and this says something about the situation of the different categories of sight impairment.

Those who become blind are, in the beginning, completely dependent on those around them, both for mobility and reading. The need to be mobile is even more fundamental than the need to be able to read. To lose this ability is, therefore more distressing. It can also be felt humiliating to be deprived of the right to decide oneself when one wants to move to another place.

The severely visually impaired who lose the ability to read are usually able to be reasonably mobile. They can, at least, maintain a degree of mobility such that the limitations are not experienced as humiliating. Not to be able to read becomes, therefore, the difficulty which is most often mentioned by this group.

Most of the partially-sighted are able to read headings in larger print. They experience, therefore, a certain intellectual freedom of choice. Their situation with respect to mobility is also more favourable than it is for the others. In spite of this the partially-sighted, like the blind, usually feel limitations in their freedom to be mobile as the greatest difficulty after the onset of their visual impairment. In their case, it is a question of a different type of mobility freedom than that relating to the blind. They do not see street signs and house numbers, and are often very dependent on the light conditions. These create difficulties in orientation. They cannot drive vehicles either.

To the question of what helped the most to overcome the difficulties which the visual imparment created, the rehabilitation course itself was mentioned most often, but no one indicated which particular aspect of the course. Above all it was judged that the course had given the opportunity for personal contact. One 35 year old blind woman said: "It was only when I met my course companions and we went out to eat one evening that I realised that I was a person still".

The rehabilitation course's primary significance has been that, negative attitudes towards the visual impairment and towards their own ego has grown milder or disappeared. On the rehabilitation course the individual can get help to master their new situation in life. However, many have experienced one or more radical changes in their life after they have come home from the course. They do not even usually have anyone to turn to when new problems arise.

The decision to begin a rehabilitation course is a step forward for the individual in the rehabilitation work. It presupposes that he is able to have hope for the future. Next time the individual comes to make a significant decision or experiences that something important for him is happening, is in connection with the choice of occupation. Then, he is not satisfied just to hope for the future without also beginning to plan actively for it.

If the individual prepares himself, through education, to come out into employment but finds that his contribution is not needed or that he has concentrated on the wrong occupation, he suffers a bitter disappointment. He feels that he has been thrown back to the same point where he had stood earlier. This makes him more distrustful and resigned when it comes to other educational directions and possibilities. He has again suffered a loss: he has lost trust in the future.

Three people out of five feel satisfied with their situation in life some years after they have received the rehabilitation help which the community offers. For those rehabilitation has been successful. But the investigation also showed that the rehabilitation of particular individuals is, at times, unsuccessful, in spite of the fact they have gone through a comprehensive rehabilitation program. The lack of co-ordination between the different measures for help and the limiting of resources for help to certain times and particular places are important factors for this. There is a substantial improvment that a teacher accompanies each pupil back to their home area and help them in their places of work as well as in their homes and immediate surroundings.

Finally Kajsa Dellgren considers that consultants, almoners or psychologists, trained in psycho-therapy ought to exist in every regional district. To these, newly blind persons and patients whose sight is rapidly becoming worse, together with their relations, would be able to turn in order to get help with the psychological adaptation to the new situation.

Ole Jensen and Hans Tage Truelsen, two Danish psychologists, have studied 100 visually handicapped men's social roles and well-being. They think that the difficulties of the visually handicapped have shifted from economic problems to more psychological and social effects consequential of their handicap. Their research is a qualitative socio-psychological study on these consequential effects, and it includes the practical difficulties and problems encountered by the visually handicapped, the role in society of a visually handicapped person, their role conflicts, the manner in which they accept their handicap and an elucidation of the mental well-being of visually handicapped persons.

The importance of the visual handicap to the person concerned will depend not only on the degree of his impairment, but far more on his own attitude to his handicap, as well as on his environment and whole living conditions. Although the difficulties may be more or less severe for the different groups of visually handicapped men, it would appear that certain features are general for all. They have to use more energy and time for the performance of their actions. They have to concentrate more in order to be able to perform these actions and they are generally more dependent on other people.

The difficulties which the visually handicapped person meets at his place of work are in part purely working problems in connectio with the performance of his functions, but he also encounters problems with regard to his relationship with his co-employees, being obliged as he is to depend on their goodwill and help in certain situations.

Many visually handicapped men are finding themselves being offered the least attractive jobs, such as the less well-paid jobs or the jobs at the lower end of the job-hierarchy. It was also indicated that, due to their visual handicap, they had to put up with the conditions of their places of work to a greater extent than is necessary for the sighted employees. The visually handicapped have greater problems if they are dismissed, due to the shortage of jobs available to them.

Certain conditions are of decisive general importance for the mental well-being of visually handicapped men, whereas other conditions are of more importance for the well-being of certain groups of visually handicapped. The visually handicapped man will - other things being equal - thrive better (have a better well-being) if he 1) has an openminded and rational attitude to his handicap and consequently, better possibilities of being able to fulfil himself as a human being, 2) has a job of work to enable him to step out of his role of a visually handicapped man and 3) has no sight left at all.

In the third condition the person in question is more clearly confronted with his handicap. When faced with various situations he will not hesitate - as is often the case for persons who still have some vision left - in his decision on whether he should endeavour to cope with the situation on the basis of reduced sight or whether he should tackle the situation in the way that would be natural for persons with no sight at all. On average he is also superior with regard to making use of his other senses, especially the senses of hearing and touch. On the other hand, neither the age of the person, his civil status, his residence nor the time in life at which the reduction of sight has occurred, would seem to be single factors with any bearing on the mental well-being of visually handicapped men.

From a psychological point of view the difficulties and problems of visually handicapped men with regard to their personal self-asstertion lie in two main factors: 1) the attitude of the person to his handicap and 2) the social role which he feels is being imposed upon him by the sighted - the role of a visually handicapped person, and the great deviation of this role from that of the ordinary man in society.

The two factors are of mutual importance. The attitude of the person in question to these factors becomes decisive for his ability to fulfil himself as a human being, for his mental well-being and for the shape of his whole future life.

LIVING TOGETHER THE SIGHTED AND THE VISUALLY HANDICAPPED

A thesis in Psychology - Summery of a report

A man becomes blind or partially-sighted but must learn how to live with being visually handicapped. When something happens to a person which is so intervening on their life as to lose their sight, totally or partially, then it doesn't only affect the visually handicapped person himself. The adjustment to this changed situation also involves the sighted people around him, first and foremost those nearest to him, i.e. his family. Without the help from other peoples' experiences the "transformation" process can be a very difficult problem for both the visually handicapped person and the sighted members of his family.

The report is based on answers from 18 married couples on questions describing their experiences about how their situation changed from when they began living together as a sighted couple until the time one of them had become blind or partially-sighted. As far as we are aware, no investigation of a similar character has been carried out, which also includes the experiences of sighted people involved in the situation of their marriage partners losing their sight.

The couples were aged between 31 and 66 years of age. They had been married at least three years before the loss of sight had occurred. The couples had 32 children in total. We were also able to talk to

For just over half of the couples interviewed - for the sighted as well as visually handicapped - a change had occurred with respect to their work, for the majority as a direct consequence of the situation involving sight impariment. Out of the 18 interviewees who were still sighted, 15 were employed before their partner lost his or her sight. Out of the 18 who became visually handicapped, 14 had had employment when they were sighted. At the time of the interview, however, 14 of the sighted and only 5 of the visually handicapped were employed on the open market.

All had experienced quite good health, on the whole, before the occurrence of their sight impariment. This had changed, however, at the time of their interview. It appeared that men coped with the situation best, expecially if they were the sighted one.

Whether the women were sighted or visually handicapped, the occurrence of visual handicap was considered to involve a greater strain on her as a result of the traditional differences in upbringing of boys and girls. Men were considered as being easier to take care of by their wives when their sight failed, while it wasn't so natural for men to help their wives in the corresponding situation.

More than half of the interviewees were satisfied with the way they at the hospital learnt about the serious condition of their eyes. With respect to getting information about assistance in "living" with visual impariment, one person preferred to have an "ophthalmic nurse" . This person was blind and had been under ophthalmic care for a large part of his life and had developed a good "rapport" with the nurse there. Six preferred to get information from a medically qualified eye specialist. Nine would prefer to optain such information from a psychologist, although none of these had ever met one. Twelve would prefer to optain such information from an almoner (social worker), but this wasn't so for those few who had actually met one in this connection. Many considered that whoever it was that gave such advice, they should be specially educated in the problems that the visually handicapped could meet in their experience of being without, or with imparied, sight. There is no such special education in Sweden for either doctors, psychologists, nurses or almoners.

No uniform reference procedure exists between those involved with the treatment and care of sight and the Swedish Federation of the Visually Handicapped district consultants. Whether the visually handicapped person gets to meet a district consultant depends, therefore, on the ophthalmologist's judgement, the visually handicapped person's attitude to the meeting, his own initiative, etc. Usually the visually handicapped have little knowledge of what help can be given to him by the consultant. Once contact had been made with him, however, the majority were positive to a visually handicapped consultant, which usually reflected the attitude they had towards him as a person. Half of those interviewed thought that the consultant's information about talking books, magazines, and newspapers was the most useful.

Scarcely 20% of the visually handicapped who are registered with the Swedish Federation of the Visually Handicapped have the opportunity to participate in any of the adjustment courses which exist in a few places in Sweden. Fewer than half of those interviewed had taken part in a rehabilitation course of either long or short duration. The women had been able to do such courses to a considerably less extent than men. These courses take place too far away from home for the majority. Almost all thought that the seeing also needed to be able to learn how one can help a visually handicapped person. This implies, consequently, that there should be some sort of adjustment course for the seeing, as well.

In the report we describe the couples from different aspects. In the section "In the home" we have focussed on possible changes in the sharing of activities and experiences at home. All of the sighted men experienced some change while only about half of the sighted women did. Among the blind women there were four out of five who experienced some change in the running of the home - all four in a negative direction. With respect to getting information from daily newspapers, the blind women experienced a change for the worse. This also applied to the partially sighted women. Both seeing and blind men were happier with the information they got from the daily newspapers. Four out of five partially sighted men, however, did not get the information they wanted from the daily papers.

With respect to the couples interests and friends, all the blind men still had a majority of sighted people in their circle of friends. All the visually handicapped men thought that they had had common interests with their wives before their loss of sight which they couldn't continue together now. The sighted women were also of this opinion, although to a lesser extent.

The couples "aoutside the home" showed that 6 out of the 7 partially sighted, and 3 aout of the 9 blind, go out by themselves to some extent. It was thought by the visually handicapped too difficult to go out alone, even by those who had gone through a rehabilitation course and had learnt the "white cane" technique there. No follow up had occurred, however, in their home areas.

None of the partially-sighted women carried a white cane visibly when they were out together with their husband, and only one of the partially-sighted men carried one in the corresponding situation. All the blind men carried a white cane visibly when they were out with their seeing partner, as did three of the five blind women.

A sighted person's description of the surroundings for a visually handicapped person can, for many, be a stumbling block. The sighted must learn to see in a different way so that the visual images can be changed to words that the visually handicapped can perceive as an "internal image".

Judging when the visually handicapped need help is another very important area. Underestimation of a visually handicapped person's ability to do something is more usual than to overestimate it. This applies especially to blind women. Three of the five blind women thought that their own estimation of what they could manage agreed "very occasionally" or "never" with what their husband thought.

The ability to be able to experience nearness to one another is important. We describe this from the aspects of eye-contact, physical contact, suxual life together, experience of personality changes, mutual understanding, and to what extent the couples were able to talk to each other about difficulties arising from the loss of sight and their mutual life situation.

The change from having lived together earlier as a sighted couple to the present situation of one of them having lost, either partially or completely, their sight, causes problems in itself. The independence-dependence aspect is easily displaced from its earlier balance between the couple. To give and receive help becomes everyday situations in the changed existence. Similarly, the balance between activity-passivity is displaced for both partners. All this must be met in a new way. Both must re-learn, and continue to live according to a different way of acting and reacting. In addition, it is necessary that both are able to change their thoughts so that they can be flexible in their view of themselves, each other, and their surroundings.

To the question of what might help a family which found itself in the situation of one of the parents having become visually handicapped, one young man replied:"I should imagine that someone who wasn't a member of the family should be sort of involved in it, so that a new element came into the picture, someone who could sort of explain what it was all about so that you didn't need to experience everything practically first, but rahter you were a little bit prepared. I didn't have any explanations at all about what happened to a person when he losis his sight. Instead I had to pick everything up pracically from each situation which came up, and that was a real burden".

In order to reduce the problems the "visually handicapped family" is faced with in such a situation, we propose that ophthalmic care be extended so that the patients have better opportunities to discuss the condition of their eyes and what the new situation will mean for them - medically, economically, and social-psychologically.

The partially-sighted should have better opportunities to utilize their residual vision through more established optical aid centres. The visually handicapped should have better help to find a work and to find other activities. Organisations working for the visually handicapped should also do it from the visually handicapped's immediate social milieu, and also include the sighted member of the family.

With increased knowledge follows a higher degree of understanding. Thereby follows also better conditions for the visually handicapped to continue a rich and stimulating life. How other people in the society meet the visually handicapped and their sighted relatives is also very important. Therefore all need increased knowledge about visually handicapped and their situation. They become then more prepared both for themselves and others.

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THE VISUALLA HANDICAPPED FAMILY AND THE ENVIRONMENT

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INTRODUCTION

By way of introduction, I wish to point out that this lecture is not based on scientific investigations or literature studies but entirely on experience acquired through twenty years of work in an organization of blind and through a life marked by a severely impaired eyesight and through a marriage in which both partners suffer from severe visual impairment. The reason why this method has been chosen is first and foremost of practical reasons. The group we deal with here is according to our experience so small on a national level that it is very difficult to advance research results in general apart from a very few and very concrete questions.

DEFINITION

In the first place, let us establish which group of people we talk about. In Denmark, we have an official definition of blindness of 0.1. The faculty of vision is measured with the best possible correction. If the faculty of vision is above 0.1, the person will still be defined as blind if serious complications reduce the residue of the eyesight to 0.1 or less.

As far as the definition of partially sighted is concerned, there is an official definition but in general a marginal value of 0.3 is employed.

This paper, however, only deals with the group legally blind.

Viewed in relation to the family situation, this group can be divided into families where both husband and wife are blind and families where only one of them is blind. In the last-mentioned case is distinguished between whom of the spouses that is blind. I will give the reason later. The problems for families where both husband and wife are blind but where the children are sighted will also have to be looked into and also for families where both of the parents are sighted but where one or several of the children are blind.

Finally, it should be mentioned that the definition environment in this connection can best be understood in the way that the physical as well as the social environment are taken into consideration.

SOCIAL ASPECTS

Severe visual impairment causes a great deal of interference in the personality and the possibilities of development for the individual because visual impairment causes complete or partly dependence on other people in many ways.

This situation is naturally more marked in cases where both husband and wife are blind and where even commonplace, daily functions cause problems, but also for married couples where one of them is blind the dependence plays an important role.

In families where both husband and wife are blind there is the "advantage" that both parties are placed on an equal footing and therefore help each other on equal terms whereas this is not the case if only one of them is blind. In the socalled mixed marriages, the greatest difficulties arise in the cases where it is the wife who is blind. In spite of the strong emancipation which has made itself felt during the past twenty years in the Western countries, it must clearly be admitted that according to the pattern of sex role it is still taken for granted that the wife is the most important working power where it is a question of domestic work and child minding. It is often discussed which kind of employment the blind can undertake and the difficulties which must be overcome are enumerated. It seems, however, to be taken for granted that domestic work can be done by every blind woman although in reality it may be the job which involves the greatest difficulties for a blind person. To this can be added that apparently it is more difficult for men to accept a situation which implies a higher degree of joint efforts about such tasks and, last but perhaps not least, every man is dreaming of being married to the perfect woman and the blind wife has in any case a severe defect in this respect, i.e. that she cannot see. This viewpoint can be underlined by the fact that the divorce rate is higher among such marriages than among marriages where it is the husband who is blind.

Another aspect of blindness can be mentioned as a striving towards conformity. In a home where both husband and wife are blind, it can be noticed that an effort is made to design and decorate the residence according to the custom although the inhabitants of the residence cannot enjoy the design directly. The basis for this effort is, of course, partly a desire of having a home as everybody else's for one's own sake but the intention is also to make visitors feel comfortable. The achievement of this effect can often cause difficulties because the ideas and intentions the blind has in mind can be difficult to explain to the sighted person or persons who shall help to realize the ideas. This often means some uncertainty for the blind.

The same problems arise in the case of personal matters. How about one's clothes, are they clean, do the colours match, how about following the fashion, etc. It is obvious that for some of the matters certainty can be obtained either by the help of a sighted spouse or by help from outside, but has the helper now a reasonably good taste, is he or she able to match the objects to a proper whole?

Above is mentioned many practical problems which a family encounters to a higher or lesser degree if the family is burdened with a visual handicap. What about the social relations for such a family?

During the past twenty years, great efforts have been made everywhere in order to integrate the visually handicapped in the normal community because it has clearly been realized that isolationism in this field as in other fields causes adverse effects.

Integration means, however, problems for the visually handicapped as well as for the sighted. In reality, incompatible dimensions have to be united. The world we are living in is on the whole planned on the assumption that the citizen has a normal sight and, therefore, the visually impaired has to make a considerable effort to be able to function in this visual world at a reasonable level. On the contrary, to be able to see is a natural thing in our communities and the lack of this capacity is difficult to understand and this causes that the sighted has a strange feeling towards the visually impaired and the special problems he or she has.

If you imagine that a family with severe visual problems establishes itself in a normal residential environment and tries to integrate itself in these environments, the first and most difficult task is to teach the neighbours to understand the character of the handicap and thereby the possibilities and the limitations the handicap causes. This implies that the disabled person possesses a considerable physical strength because naturally it is always difficult to confess that one is a deviant and that there is a number of perhaps even commonplace things one cannot do. Among other things, the difficulties are based on the fact that in general human beings pass fast judgments and draw hasty conclusions without having looked carefully into the problems.

As mentioned above, the community is organized for the sighted and this fact faces, of course, the visually impaired family with tasks which the family is in reality unable to solve. The result is often that the life of the family with a visual handicap cannot be based on the many offers which are otherwise at the disposal of the population but must be built up on other standards of values and on practical possibilities. Compared to the life of the sighted population it often means a more poor life in any case as to quantity.

THE PHYSICAL ENVIRONMENT

As already mentioned the modern community is organized for the sighted and therefore presents the blind for a number of difficult or insoluble problems. In passing, it should be mentioned that the well trained blind has reasonable possibilities to function in an employment although with narrow limits and has thereby the possibility to ensure the social status which a commercial employment gives. The problems of the utilization of our community are concentrated

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especially on two main fields, namely, firstly, the activties necessary in order to make the material life of the family function, secondly, the family's utilization of the recreation arrangements.

If a family shall function, it is necessary that shopping can be done of daily consumer goods as well as of more durable consumer goods. The organization of the retail trade in the modern Western countries makes it impossible for the blind to do such shopping without help. It is, of course, impossible for a blind person to manage the shopping in a supermarket without help and it is just as impossible to ensure that this help can be so efficient that the blind can utilize the competitive offers and other competitive initiatives of the shops in order to ensure as economical a housekeeping as possible. As to the durable consumer goods, it is impossible without help to get a general idea of the market and thereby be sure of a good bargain of the article wanted.

The recreation activities of the normal population can broadly be divided into two main groups, namely outdoor and indoor activities.

Outdoor activities are sports, camping and gardening. The greater part of the activities cannot be done without the aid of the sight unless special measures are made and this can only be done in very few cases.

As a consequence of the economic growth, it is now customary in many countries that a family has at disposal two residences, namely one residence in town and a weekend cottage in the country. This means that the cities to a large and steadily increasing extent are depopulated outside the working hours and especially during the weekends. This way of life necessitates, however, that the family is motorized. Of obvious reasons, the visually impaired cannot be motorized without help and will therefore either be left in town or a new state of dependence will occur.

Should this development continue, it will cause rather large social problems. The development will not only cause general changes in the structure of the community but it can also be expected that many of the cultural activities at disposal in a community will be moved to the places where the citizens are in their leisure time so they have a possibility to utilize the offers. The consequence will be that immobile groups of the community will be left in the empty city centers without life.

As far as indoor activities are concerned, the possibilities are, of course, much larger because the dependence is more or less limited by the nature of the activities. The problem in this connection can best be illustrated as lack of information. A great many social activities need access to written material to a larger or smaller extent and even in the best equipped countries the blind's supplies of written information are insufficient. This means an essential obstacle to an integrated participation in the activities.

What can be done about these problems? Let us establish that only exceptionally it is possible to solve the above problems through an efficient rehabilitation of the sight. The starting point must therefore be that the visual impairment is a lasting condition in a minority of the population. The main principle in order to improve the conditions must therefore be to plan the community in such a way that the arrangement of the community at least does not put unnecessary obstacles in the way of the visually impaired. It goes without saying that the visually impaired must be trained in the best possible way and have the best equipment of technical aids but the proper development must be through a more adequate planning of the community. Actually, a community consists of many minority groups which together form the population of a country and therefore the arrangement of the community should be planned out of regard to the minorities. What is being done, however, is to plan the community from the qualifications which young, physically, psychically and intellectually well equipped citizens possess and then it is demanded that everybody else shall adapt themselves to this community. I will just mention a few examples of such an inconsiderate planning. In order to rationalize the town traffic, the speed of the local trains is increased and the stops at the stations are made shorter with the result that the locomotion retarded (handicapped, old people, mothers with children) have difficulties in using this means of traffic. Where there are shifting of level, stairs are established instead of ramps. Information, often of a vital nature, is given in the form of signs, although about 10 per cent of the population have difficulties in reading owing to a reduced sight (here is included the group of old people and the group of word-blind). The examples are legion but let us stop now.

THE FAMILY WITH CHILDREN

As previously mentioned, we must also in this connection mention some of the problems which families with children encounter.

In a family where the parents are blind and the children sighted, there will of course arise considerable difficulties. Firstly, it will be difficult for the parents to ensure that their children get very varied and rich experiences so it is very important indeed that the children get the opportunity at an early date to visit an institution for children so they can get the impulses which a sighted environment can give.

During schooling there will also be difficulties because in many cases the parents will be unable to help the children with the school work and thereby they will be cut off from an important part of the life of the children. On the whole, gradually as the children grow, a serious risk arises that the parents, respectively the children, establish a life of their own.

Finally, for the sake of good order, it should be mentioned that great problems can arise by the fact that sighted children have to be sighted assistance for the parents to too large a degree and thereby the children are partly cut off from the companionship with other children which can result in social difficulties.

In families with sighted parents and one or several of the children with visual impairment there are of course also difficulties. The parents are in need of assistance in the opbringing and also of assistance of a pedagogical nature. The assistance must be given to the parents who shall be made able to solve the problems as well as to the child who as early as possible must learn to compensate for the handicap. Such assistance must naturally be placed at the disposal to a sufficient extent by the community.

It must be stressed that especially the assistance to the parents is of great importance because an ordinary sighted pair of parents is hampered by the attitude towards the invalides in the normal community and, unfortunately, these attitudes will often contain some negative elements which must be corrected as soon as possible.

CONCLUSION

The community has changed its attitude towards the visually impaired to the effect that the development turns away from care of the blind in the institutions towards integration in the community. This development has many reasons of which after all the most important can be said to be a desire to humanize the life of the visually impaired by including him or her in the solidarity.

The community does not, however, seem prepared to make the necessary measures to fulfil the objective or put in other words the community has not realized which measures it has to provide in order to achieve the objective.

So far, the community has aimed at the quite obvious measures and further to this an effort has been made to trim the visually impaired so that he or she will fit into the existing frames.

If the wishes of integration shall be taken seriously, the complex of problems has to be reverted and the community should be arranged so that the visually impaired can function in it on their own conditions. The planning of the community must comprise the public as well as the private sector. It is obvious that this will mean higher costs in many fields, but these higher costs are community costs. Integration also means equality and the equality of the handicapped people with the non-handicapped can only be obtained provided the handicapped are treated "better" than the non-handicapped.

SPECIALISED SERVICES FOR THE BLIND

Edward J. Venn

Whilst wholeheartedly believing that blind people should be integrated into the community so that they share in and contribute to the life of society, the paper raises the question as to whether services for blind people should be integrated with those for other disabled people.

It discusses the specialist services for the blind by way of schools, rehabilitation centres, training establishments, employment placement services, sheltered workshops and social work generally. Reference is also made to the need for a Blindness Allowance to be paid to all blind people to enable them to meet the extra expenses imposed in so many ways by the effects of blindness.

The author suggests we must maintain the highest degrees of specialisation in blind welfare work but, in so doing, must be aware of and take advantage of the services for the community as a whole. The distinctive needs of the blind must never be overlooked within the generic framework of work for the handicapped and the community at large.

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Deputy Director-General, Royal National Institute for the Blind.

SPECIALISED SERVICES FOR THE BLIND

Edward J. Venn

If you ask most people if the blind should be segregated, the answer would be "No". As a general policy the Royal National Institute for the Blind and others all believe in the integration of blind people into the community so that they fully share in and contribute towards the life of society.

But are we so sure that services for blind people should be integrated with those for other disabled people? Historically and traditionally most services for blind people have been provided separately from services for other disabled people. Certainly in Europe - and I suspect throughout the world - planned services for the blind have been developed in advance of services for the disabled generally. Equally, I think it is well recognised that the services for blind people have paved the way for organisations working for other classes of handicapped people to develop their services.

But in today's world should such a policy of highly specialised services for the blind - at its extreme isolated from services for other handicapped people - continue? Is this the right policy? Certainly, again historically, the policy of segregation has paid dividends. Blind welfare services have been advanced to a high level of development, and blind people have much to be proud of in that - when we talk about the younger groups of blind people - they now enjoy opportunities to be well educated, well trained and become good employees in professional, administrative, commercial and industrial occupations. And there is no doubt that the special schools for the blind, the special residential rehabilitation centres for the blind, the special training establishments for the blind, the special employment placement services for the blind, the special sheltered workshops for the blind, and the special local Home Teaching and Visiting service for the blind, have played their part in bringing about such achievements. And it would need a brave person to say today that all these highly specialised services which have been - and still are - so successful should be altered to a system whereby the blind were educated, rehabilitated and trained exclusively alongside other disabled and/or able-bodied people.

In my mind there is no doubt that the blind have special needs which in most instances can best be met by special services. Of this I have no doubt and I suspect that workers for the deaf and for other classes of handicapped people believe that their clients, too, have special needs that are best provided for by their specialist services.

Chairman, Rehabilitation Commission of the European Regional Committee of the World Council for the Welfare of the Blind.
Deputy Director-General, Royal National Institute for the Blind.

And this is where I get back to my original question 'Should the blind be segregated?' I said the answer is "No - they should not be segregated - they should be integrated with the community". And by that I mean integrated wherever possible with the sighted and non-handicapped community.

So, if we are to provide special services for the blind - as I believe we should continue to do - we must make sure that the blind are not segregated from the community at large. If you believe in integration - as I do - then the special education, rehabilitation and training services for the blind must make sure that blind people are educated, rehabilitated and trained so that they may become part of the whole non-handicapped community. This has always been the policy of the RNIB and I believe it is fair to say that it has been a policy which, by and large, has been implemented. Blind people, as I said earlier, are in all forms of work and at all levels of work, and play a prominent part in the affairs of the community. I really do believe blind people have the opportunity to develop their abilities to the maximum of their individual capacities and interests - many of them brilliantly overcoming the handicap of blindness.

Let us now consider some of the specialist services for the blind.

I am not an educationist but I know that experts in this field hold different opinions on the question of special schools for the handicapped as against integrated education. Personally, it seems to be a grey area so far as the blind are concerned. I do not think that there can be any doubts that blind children need special education by way of equipment and trained staff - and whether this is provided in a special school for the blind or by way of special services in a school for the sighted is a problem for educationists. Certainly, it would seem that whereas it is relatively easy to establish a special residential school, which, of course, should give the pupils every opportunity to mix with the community, there are bound to be practical difficulties in arranging specialised resources and instruction for one or two blind children in a sighted school. I said it is a grey area and I think this is so because whereas some children will benefit most by a special school education, others will no doubt best be placed in an integrated education setting as the most appropriate means of avoiding emotional and social isolation. The decision as to whether the child is placed in a special school for the blind or in an integrated setting must however be based on a full and on-going assessment of the individual child, including the family situation, geographical location, et cetera. But what stands out under either system is the need for specialised resources by way of equipment, materials and instruction for the blind youngsters.

If we now turn to the specialist residential rehabilitation centres for the blind, again I would say that the impact of blindness, which affects every aspect of a newly-blinded person's life, is such that rehabilitation is best carried out at a centre specially established for blind people. The advent of blindness brings very many associated losses - the inability to walk, to read, to write, to perform the daily arts of living, including eating and drinking - things that one could do as a child - and very many overlapping losses, some of a psychological aspect, such as loss of confidence. The common tasks of daily life have to be relearned. Every act which was once taken for granted demands a new technique. Blind people have to start a new life at a time when they have taken a tremendous shock to the nervous system and at a time when they are psychologically and often realistically insecure. It is recognised that the onset of any serious disability leads to losses and the need for complete re-adjustment to changed circumstances, but I contend that the losses suffered by blind people are essentially different to those encountered in dealing with other forms of disability. Therefore, I suggest this rehabilitation is best carried out in the company of others who are tackling the same problems under the guidance of specialist instructors, some of whom are blind themselves so that they can bring to bear the force of example, which is more potent than anything else. So again I say a highly specialised service is essential although naturally in its organisation the utilisation of other professional disciplines in the medical, social and vocational fields is necessary.

The same sort of observations often apply to the need for special vocational training establishments for the blind, or at least to the need for special arrangements to be made for their training in an integrated setting. The techniques of learning a new job - and equipment needed for that purpose - require specialisation. Sometimes, certainly, such specialised training can be given within a training establishment for sighted able-bodied people because the blind person by that stage has already been rehabilitated, is confident and competent, and has attained the basic skills to enable him to hold his own, with such special equipment and tuition as may be required, in such an establishment.

When we turn to the question of placement in competitive employment, special facilities exist for the placement of blind people in work. This is essentially because no-one designs jobs to be performed by blind people. All work is normally provided on the basis that it will be undertaken by an employee who is sighted - the jobs are therefore based on the use of sight. However, it is now fully appreciated that in the industrial field work by way of assembly, inspection and machine operation can be performed without sight through the use of the other senses, and particularly the sense of touch. Similarly, in the commercial field, blind people can undertake work as telephonists using a tactile approach and their hearing, and can also work as audio-typists and shorthand-typists. With the growing use of optical aids, including closed circuit television, one can also expect more blind people with residual sight to be placed in clerical work. The use of the Optacon, the development of braille computer terminals and indeed reading machines, will also open up clerical opportunities with optical character recognition input and synthesised speech output. Blind people, too, enter the professional fields of work, particularly becoming solicitors, lecturers and teachers, social workers, physiotherapists, computer programmers, musicians and administrators.

In so many of these occupations, whether in industry, commerce or the professions, the use of braille linked with special equipment has enabled the work to be undertaken. The use of a braille micrometer is essential to the factory inspector or machine operator; braille shorthand is essential for the blind shorthand-typist so that she too can take dictation on a braille shorthand machine at 120 words per minute. The ability to be able to read and write in braille is also normally part of the training for the professional blind person. The use of recorded information on tape, however, is an increasing means of receiving and imparting information. In general, so often the problem of communication is solved by the complementary use of braille and tape recordings so that, with special equipment where necessary, sight as such is unnecessary to undertake the job in hand.

All these however require special expertise and the development of special aids to employment. It also demands special counselling and the provision of a specialist placement service for blind people so that employers may be persuaded to engage blind people on their staff in the knowledge that technical expertise and equipment will be available. So in many countries there are specialist employment services for blind people but, as with all our specialist services, working with others concerned with the employment of the population as a whole.

Whilst the great majority of blind people are engaged in ordinary factories and offices, working alongside sighted colleagues, some blind people however are best placed in special workshops for the blind which today in the United Kingdom have by and large changed from giving employment in a range of craft trades - baskets, brushes, mats, et cetera - to modern mechanised manufacturing industries. Many of these special workshops for the blind are now admitting sighted handicapped people so that together the blind and the sighted can produce the whole product on which they are engaged. This is fine, but I think that in setting up or running such a workshop it is essential always to have in mind the special needs of the blind to ensure that blind people can play a major part in the production of the goods selected for manufacture.

I also referred to the special Home Teaching and Visiting service for the blind which was a highly specialised service in the U.K. until the advent of the Seebohm Report in 1968 and the consequent reorganisation of many local government social services departments on a generic basis. Broadly, I favour the development of generic social work training and welcome the steps now being taken to provide specialisation within a generic framework. We welcome the introduction of qualified social workers with knowledge of blind welfare work and the acceptance nowadays of the fact that there is nothing in Seebohm to imply the abandonment of specialism in social work practice. Indeed, current policy is for the continuing development of specialist posts, namely posts as Technical Officers for the Blind and Mobility Officers for the Blind, within the generic social work team.

And so, I suggest, we must maintain the highest degrees of specialisation in our work for blind people, but in so doing we must be aware of the services provided for the population as a whole. We must take advantage of these services for the community where they will assist blind people but be constantly satisfying ourselves that the needs of the blind are being met.

There is one other aspect of special need to which I would like to refer, namely the need for special cash allowances for blind people. The organisations for and of the blind in the United Kingdom believe that all blind people should be given a realistic Blindness Allowance to enable them to meet the extra expenditure imposed in so many ways by the effects of blindness. Probably the majority of blind people in the United Kingdom receive no financial assistance of any kind from any source to offset the additional expenses forced upon them by blindness. I know that it is always a problem to decide on the extent to which social security provision should be made by way of cash or by way of direct services. As the Minister for the Disabled has said, we have to have a proper mix of cash and direct services, but it is an indisputable fact that blindness imposes extra living expenses and we believe this should be recognised by the introduction of a realistic Blindness Allowance. I appreciate that it could well be argued that other disabled people have a need for a Handicap Allowance and, if a special handicap allowance was introduced for all handicapped people including the blind, then my only concern would be to ensure that the level of the allowance for blind people was compatible with their extra costs of living. Blind people need not only the specialised help to which I have referred by way of direct services but, like all handicapped people, they need sufficient income to meet the extra expenses imposed by their handicap.

In so many walks of life, we live in an era of specialisation, and really from what I have said you know I feel that it is an indisputable fact that blind people need special resources to assist them towards overcoming their handicap. At the same time, however, I hope I have indicated that there is a broader concept and that the services for blind people must be within that overall service for the total population. Those of us in blind welfare must co-operate, liaise and communicate with other disciplines and be part of that broader concept. In a way, this conference proves the point I am making - it is a conference about the Disabled. The blind are a section of the disabled and within your conference arrangements there is this special seminar devoted today to the special interests of the blind. The distinctive needs of the blind must never be overlooked within the generic framework of work for the handicapped and the community at large.

THE REHABILITATION OF MULTIPLE HANDICAPPED BLIND PERSONS

BERNARD COOTE +

ABSTRACT

The Royal School for the Blind, Leatherhead, foremost among Training Schools for the Blind from 1799 - 1939 , found itself becoming in the early 1970's a national centre for 150 blind adults with additional handicaps for whom Social Services Departments could make no local residential provision. Being the largest such community in England and being unable to meet the pressing demand for admissions through lack of staff and facilities, it has researched with DHSS and Associations for the Blind to ascertain its future role. As a consequence Residents now enjoy opportunities to discover and develop latent skills; an experimental training programme indicates possibilities of greater independence, freedom and varied life styles, and both modernisation of the original building to facilitate this, together with ventures in participation in life in society, are being initiated.

INTRODUCTION

During its first 100 years the "School for the Indigent Blind" excelled in educating and training young blind persons for normal life and work in society. The move from London to Leatherhead in 1901 made further advances possible, in ideal conditions, for another 40 years. In the 1950's, after the disruption of war, a thriving Occupational Therapy Centre was established. However, recent admissions of more handicapped and less able residents has necessitated re-examination of the needs and hopes of the 150 multiple handicapped blind residents; an analysis of referrals for places for the growing numbers of more handicapped persons for whom the only alternative is Hospital placement, Hostels for the Sub-normal or Old People's Homes, and a realistic assessment of the possibilities of enabling residents to live normally in society with maximum freedom and responsibility for themselves. Proposals include modernisation, additional new units and the use of houses allocated by the local District Housing Department. Government assistance will be necessary to finance the project.

Other establishments in England, caring specifically for the multiple handicapped blind are The Wilberforce Home, York: 20 blind and physically handicapped, and Christopher Grange, Liverpool: 12 young women for a limited period.

BLIND PERSONS WITH ADDITIONAL HANDICAPS

(a) Who are they? Figures published by the Government in 1976 give the number of blind with additional handicaps as 23,831. This is reckoned to be an under estimate. At Leatherhead there are 150 men and women aged from 17 to 84 from 66 Local Authorities in England and Wales. All have been assessed as

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"incapable of gainful employment" and have I.Q's ranging from 50 - 100. Three have been in residence more than 60 years, many between 30 and 40 years. A half have no family and no other home. They are in residential care for domestic reasons or because of unsuitability for inclusion in local Homes or Adult Training Centres.
95 are under 50 years of age (20 - 30 age group = 35, 30-40 age group = 40).

The main additional handicaps are: Epilepsy, Deafness, (Deaf and Dumb 4), Diabetes, Spasticity, Physical handicap, Speech defects, Mental handicap, history of mental illness. Recent referrals reveal a growing need for places for more severely physically and mentally handicapped, for those with behavioural problems and, in most cases, not one but two or three additional handicaps. Referrals are received at the rate of two a month.

(b) What is happening to them? In 1976 daily occupations were: packaging; seating stools; baskets and trays; knitting; lampshade and rug making; Braille and music. Skills taught in schools for the blind have, in many cases, not been developed and through lack of incentive to achieve any form of independence many residents have lost interest in themselves and in life, and they have deteriorated and become institutionalised.

(c) What can they do? An experimental further education programme suggests that many residents can live more independent life styles and, with training, manage shopping, preparation of meals, personal laundry and basic home care. Activities and programmes introduced are:

	residents participating		residents participating
Cookery	50	Residents' Committee	14
Gardening	6	Drama	30
First Aid	16	Sewing	6
Clay modelling	14	Dancing	30
Number	3	Braille	20
Number application:		Reading	1
taught to 'phone	21	Typing	4
taught to tell time	4	Spelling	6
taught to manage money	6	Yoga	10
Money - individual bank a/c's	30	Handbells	25
Social Club	120		

Most of this has been accomplished with the help of part time staff and voluntary helpers and in almost every instance with improvised equipment and facilities.

(d) What may be achieved? Schools for blind children prepare pupils for making the most of life. In adult life every attempt must be made to realise their expectations; to give a sense of achievement and dignity; to offer experience of success and to live with limitations in an understanding and supportive setting. The Royal School for the Blind's role is to be an enabling community for the present and for future generations.

DEVELOPMENT

Development may be seen as two elements in an inter-related process. The practical element in the form of buildings and organisation and the philosophy of development in personal terms. "Develop" and Envelop" have the same derivation. To envelop is to "wrap up" - exactly what institutions did 100 years ago. Therefore to develop should be an unwrapping, releasing, discovering and becoming. Residential work must be judged on its effectiveness in meeting the individual needs of people, enabling them to reach their potential and to push out the frontiers of achievement whether they be young or old, disabled or disturbed. It is about healing and facing reality. This involves attention to the individual person with regard to:

Home Contact: to maintain relationships that are already good by including parents and relatives in the life and concerns of a member of their family in this community. To give support and assistance where there is need and to be available to initiate and sustain ways of renewing broken and weak relationships which are the cause of anxiety for many Residents. To help in coping with rejection and over protection.

Physical Needs: To provide the basic daily needs enabling sufficient attention to be given to matters such as meals, cleanliness, clothing, health and general well being whilst not being over protective.

Social Needs: To promote opportunities for Residents to find enjoyment and satisfaction in constructive shared activity both amongst themselves and in the company of the local community, paying heed to the fact that many of them cannot reasonably be expected to go out into the community independently.

Personal Needs: To support the desire to be an individual with dignity in a large community and how this may be expressed in terms of freedom, choice and privacy, whilst being someone's responsibility. To appreciate the importance of possessions the management of one's own affairs and participation in the decisions of the community.

Emotional Needs: To explore all areas of relationships with one another, with staff and with the local community. Awareness and appreciation of personal feelings and the feelings of others. Personal growth. To accept sexuality and its implications. To foster mature realtionships, cope with responsibility and live with limitations.

Educational/Occupational Needs: To enable the continuation and development of skills and interests discovered at school or before the onset of blindness. To encourage mobility and confidence and to undertake as many aspects of self care and mutual care as possible. To achieve more independent life styles in daily living. To offer opportunities of choice and decision making, according to interests and abilities, for personal fulfilment.

OBJECTIVES

The community at Leatherhead is needed by the nation to provide a way of life that will be as normal free and fulfilling as possible bearing in mind residents' need of periods of individual attention and support. It must encourage integration in society whilst recognising that society may not be geared to meeting the special Occupational/Leisure requirements of multiple handicapped blind persons. It is necessary to begin where we are with 150 persons in a building not designed for its present use. There is little space or privacy for residents in their rooms, a lack of accommodation for an adequate number of resident staff. Although a three storey building, it has no lifts and is uneconomical to maintain. The Charity has insufficient resources to begin again in new buildings or to finance a modernisation programme without substantial Government support. After much discussion it is now accepted that a community for 150 multiple handicapped blind persons, whilst subject to some dangers of an 'institutional' pattern of life can, if comprised of small autonomous units, provide a more varied and imaginative life style than is available in smaller homes. Attention can be given to training individuals and groups with particular needs, and there is the possibility of great flexibility and combination of programmes together with economy in providing specialised and expensive services (e.g. medical) and equipment (e.g Low Vision Aids). There is the enjoyment and appreciation of relationships between young and old because of the wide age range. It is important to encourage integration with the sighted but some activities e.g drama, physical education and hobbies for multiple handicapped blind persons require special conditions otherwise they easily appear, quite unintentionally, as failures by comparison with the sighted. Consideration also has to be given to the distress that would be caused if present longstanding relationships were suddenly disturbed by moving into strange new surroundings.

PROPOSALS

By modernisation, and some new building, small autonomous units can be created giving privacy and independence. Each will have kitchen, dining and leisure space and some accommodation is designed for married couples as and when the need arises. It is essential to give maximum participation in the decisions and the running of the community. Use will be made of accommodation offered by the Local District Housing Department to enable as many Residents as possible to live amongst the local community with access to special facilities for occupation and leisure.

CONCLUSION

The Royal School for the Blind is at the beginning of a new era in its history. Many initiatives have been taken towards this experiment in rehabilitation and independence and the response is encouraging. This work increasingly requires individual care and attention by experienced staff both for the young who are developing and for older persons who for various reasons are less and less able to cope alone. Continuing and imaginative physical, mental and spiritual stimuli are needed to promote achievement and satisfying experiences of life. Small private Charities have pioneered such projects in the past and will continue to do so, given a proper measure of national support when trying to meet a national need.

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DEVELOPMENT OF INDEPENDENT DAILY LIVING SKILLS AND GENERAL MATURING OF SEVERELY HANDICAPPED YOUNG PERSONS

*Barbara Newman and Jill Vernon

Improvements in surgical treatment on babies with spina bifida and hydrocephalus in the early 1960's dramatically increased the number of survivors and for the first time there is a significant number of teenagers and young adults severely handicapped by spina bifida and hydrocephalus. These young people and their families face numerous problems including social barriers of incontinence, and inadequate preparation to take advantage of opportunities for further education, training, employment and leisure. Positive action had to be taken in the form of Independence Training Weeks for young adults, aimed at developing social independence - managing urinary appliances and routine daily living tasks. This type of training programme could be developed, not only for young adults but taking in younger children in school, to ensure that they are able to take full advantage of opportunities in adult life.

THE NATURE OF THE HANDICAP AND TREATMENT:

Spina Bifida Cystica is a congenital malformation of the spinal cord, of the meninges covering the cord, and of the backbone which normally encloses and protects these structures. This results in a swelling (containing cerebro-spinal fluid) in the midline of the back.

There are two main types. The first, and least common, is called meningocele. Here the swelling consists of fluid and membranes but the spinal cord is usually undamaged, and there is very little resultant disability. The second type of spina bifida, myelomeningocele, is more common and much more serious. In this form the swelling also contains the imperfectly formed spinal cord, and there may be varying degrees of paralysis of the lower limbs and sensory loss. Many children suffer from urinary incontinence, depending on the level of the spinal lesion, and some are doubly incontinent. Boys can usually be fitted with a penile appliance to cope with urinary incontinence, and many girls have a urinary diversion operation, so that the urine can be collected in a bag via a stoma on the abdomen.

Many babies have deformities of the legs, feet and hips, and some have spinal deformities such as kyphosis causing abnormal curvatures.

Hydrocephalus- commonly known as "water on the brain" - arises if there is an obstruction to the normal circulation of cerebro-spinal fluid within the brain. Approximately 80% of spina bifida babies

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are also affected by hydrocephalus although either condition may occur alone.

The more severe cases of hydrocephalus are treated by insertion into the head of a shunting device (valve) to drain excess cerebrospinal fluid and thus reduce pressure inside the brain. Vigilance is required in recognising a blockage in the valve, which could cause blindness, severe mental retardation or even death very rapidly if not treated. Such a blockage means immediate admittance to hospital for a further period.

With the introduction of surgery in the early 1960's to insert a valve, more babies with spina bifida and accompanying hydrocephalus survived , and the bulge of these survivors is now in the age group 10-15 years. At the time of treatment the future for these babies, particularly in terms of intellectual function, was unknown. Indeed, with such a low survival rate previously, very little was known at all about the effects of hydrocephalus. The families of these children began to care for a physically handicapped child without realising the associated problems of mental handicap they were going to meet.

Before 1960, many who survived with spina bifida had been able to take an active part in life, for example had university degrees, held full-time responsible jobs, and married. Many young people leaving school now will not have the same physical and intellectual capacities.

FROM CHILD TO ADULT:

As children passed through nursery school and on to primary education, it became apparent that hydrocephalus, although controlled, was causing "hidden handicaps" to their intellectual development. These include poor concentration, poor hand control, spatial difficulties, ocular defects and a passivity and lack of motivation, particularly after the onset of puberty. Individual children may show a mixture of these difficulties and to varying degrees. In general, young children with spina bifida and hydrocephalus are gregarious and outgoing, and their ability to chatter without substance gave rise to the description "cocktail party syndrome". This initial friendliness and high spirits is often regarded by parents, and occasionally by teachers, as an indication of overall brightness, that is to say, intelligence. It is sometimes difficult for teachers in special schools to convince parents that their children are of low ability, and this causes disputes between family and school at a time when mutual support and cooperation are vital to prepare the child for adolescence and adulthood.

With such a high standard of care necessary to achieve survival, it is not surprising that many families are unable to see their children as young adolescents with all the insecurities, hopes and urges of their able-bodied peers. The need to protect a young person from potentially hurtful relationships and situations where they might be at risk, reinforces the isolation which may already exist, particularly on leaving a residential special school. If the handicapped child is the first born, parents may have decided not to have more children, and they may have no experience of normal child development. This contributes to an overprotective attitude. The bond forged between mother and child during the early years - to the exclusion often of husbands and siblings - makes any gesture towards freedom on the part of the young person seem rejection of his mother. Yet many mothers are still changing the urinary appliances of teenage sons and daughters and give little thought to the young person's need for privacy.

Incontinence, if not managed successfully, can be the most depressing and soul-destroying of problems. Unfortunately, it is a cruel fact of life that no-one is likely to want to make friends with you or employ you if you smell! It is absolutely vital that children should learn to take responsibility for coping with their own incontinence as soon as possible. Recently, several cases have occurred where young people have fought hard to gain employment or a place at a training college, only to be sent home again because they were incapable of coping with their incontinence.

We all learn by making mistakes - disabled children need to do this too. Often gestures towards independence are quashed after the first tentative steps have ended in failure. It is all too easy for a mother to be proved right when a first solo trip to the shops by wheelchair ends up with the youngster tipping up in the gutter!

ASBAH'S CONCERN:

ASBAH in its role of providing support services for families with a handicapped member, has been greatly concerned at the distress of parents and the lack of guidance as their handicapped son or daughter approaches adolescence. Finance was found to start a Young ASBAH group, and within this framework several projects were begun with a view to providing preparation for life. One such project was a new series of booklets aimed at young people. The first book, "Sex and Spina Bifida", produced in co-operation with SPOD, is about to be published. More modestly, a Newsletter was begun to encourage young people to share views and leisure interests. However, a suggestion from a group of young people at the 1977 Spring Conference in Nottingham that they would like a chance to see how they would manage alone with day-to-day living, led to a major development - a pilot scheme of Independence Training Weeks.

INDEPENDENCE TRAINING PROGRAMME:

Two groups of 8 young people were selected to go to Five Oaks, (ASBAH's house in Yorkshire). The first group were those young people whose initial suggestion had set us thinking. Aged between 16 and 21 years, they came from all over the country. As self-selected guinea pigs their abilities and expectations varied enormously. The second group came from Yorkshire and North Humberside, again aged 16-21, and were referred through schools, social workers and Local Associations via the ASBAH Field Officer in that area. Each family was visited by the Field Officer beforehand to explain the programme and find out the individual's needs. It was hoped in this way to match the course members' abilities.

Each course lasted for one week. In the mornings the majority of time was devoted to helping the young people develop their own personal care routines. The nursing staff at Five Oaks and an appliance nurse from Downs Surgical Ltd, were involved in teaching them to manage their own incontinence - bowel management, learning to empty and change appliances regularly, being responsible for their own prescriptions for supplies, remembering to drink adequately, etc., and also learning to avoid and check for pressure sores.

A therapist was available to assist with teaching other basic daily living skills - transfers to baths, toilets, cars, etc., and giving advice with other problems such as dressing, climbing steps and wheelchair maintenance. The young people were alsoresponsible for their own laundry, (particularly important if you are incontinent), and learnt to use washing machines and driers.

The rest of the day was spent on more general aspects of independence - learning about nutrition, planning menus, budgeting and shopping, and finally actually cooking meals and learning to cope with the restrictions of a kitchen not specifically designed for wheelchair users. Students from Ilkley College joined in the shopping and cooking and invited the course members to spend an afternoon at the college, where they attended some lectures and explored the student facilities.

It had become apparent in talking to young people that one topic they particularly wanted a chance to discuss was personal relationships and sex. Representatives from SPOD and the Marriage Guidance Council were able to assist with both group and individual counselling. Discussion sessions were held on different aspects of employment, including the work of the careers service, DRO'S, followed by films and a visit to a sheltered workshop.

Course members organised their own social activities in the evenings such as arranging access to a cinema and having a meal at a Steak-house. For some it was a new experience not to be accompanied.

In reviewing the course at the end of the week, the young people expressed their determination to take more responsibility at home and to convince their parents of their abilities.

The training courses here were for young adults, but ASBAH is now expanding this programme to include courses for children from the age of 10 years. Obviously independence training should start within the family from a much earlier age, but this is not so easy in practice. Often parents are not sure of the best ways of teaching their own children, and don't have the patience or time to let a child dress himself if this process is going to take two hours! Also many children are lazy and take advantage of the fact that parents may not know how hard to push them! Thus courses away from home are necessary, combined with detailed follow-up with families and schools after the course, so that children continue to practise newly acquired skills. Together with pre-course visiting, this follow-up is essential if the week is to be really meaningful to an individual. ASBAH is concerned that no facilities exist for systematic follow-up procedures to be established through Local

Authorities. These must therefore be developed through a voluntary system of interested "friends" and links with other voluntary organisations.

WHAT ELSE CAN BE DONE?

Emphasis has been placed throughout on encouraging young people to make their own decisions and mistakes, and to begin to take responsibility for the course of their own lives. The recently published Report of the Warnock Committee on Children with Special Educational Needs includes as one of its three priorities the expansion of provision for handicapped young people in the 16+ age group, including provision for living more independently of parents. Hopefully, if this recommendation is acted upon, more choice will ba available for the more severely disabled young person, particularly in the form of extended education allowing more time to mature and develop socially and a variety of sheltered housing within the community.

The "bulge" of young people will be leaving school from now until approximately 1983. They cannot wait for this to happen "when possible" - a favourite term in Warnock. For "when possible" you may read "too late". The Association would like to see more help provided by specialist support workers - social workers, health visitors, home liaison teachers, etc., to help the family with a disabled member to accept the need for independence.

Many schools pay lip-service to independence in theory but in practice special schools need to develop a more positive approach to independence with appliances and daily living skills. ASBAH should not need to run independence courses! Introduced at an early enough age, it can be included in the curriculum, and teachers must see it as an essential element of learning, and not a mystical subject solely the perogative of the school nurse or therapist. How many teachers know what goes on in that "little room down the corridor at breaktimes? "

Accessible counselling services are desperately needed to enable handicapped young people to discuss their personal and sexual problems.

More information must be made available to individuals on the nature and implications of their particular disability. This may have been explained in depth to parents at an early age, but needsto be given on several occasions to the adolescent, preferable without parents being present, to allow anxieties and questions to be voiced.

Local initiatives such as Independence Training Weeks can be organised with a little co-operation between health, education and social services departments. Already several Local ASBAH Associations, in conjunction with youth organisations, children's units in hospital, and special schools, have held or are making plans to run similar schemes. Such local initiatives are all the more valuable as the follow-up is more easily organised. ASBAH nationally will continue to expand its programme and hopes to train therapists and nurses who would be willing to offer two to three weeks per year. Financial sponsorship is essential from Local Authorities. Intensive work on a one-to-one basis is costly.

If these problems are tackled early enough, perhaps the next few years' school-leavers may be able to take full advantage of opportunities for further training, employment and a wider range of leisure pursuits.

Seminar 4

Organised by the Royal National Institute for the Deaf

DEAFNESS

Chairman: *Mr. J. Foote*

Rainbows after Storm—The Rights and Responsibilities of Deaf People who are also Blind

Dr. Richard Kinney

Chairman: *Cllr. J. T. Rogers*

Film: 'Psychiatry for the Deaf' with introductions

Dr. J. Denmark

Chairman: *Mr. Roger Sydenham*

Excluding and Including the Deaf (from and into the family circle)

The Rev. Canon T. H. Sutcliffe

Chairman: *Mr. P. C. Trietline*

Title of Paper to be Confirmed

Mme. Chalude

FREE PAPERS

Chairman: *Mr. G. Gilbertson, CBE*

Mobility Needs of Disabled People in the UK—A Formal Sample Survey

R. W. Gormley/Larry Walters

RAINBOWS AFTER STORM -- THE RIGHTS AND RESPONSIBILITIES OF DEAF PEOPLE WHO ARE ALSO BLIND

DR. RICHARD KINNEY

Colleagues and Friends:

We have before us an intriguing question -- am I here from America to help rehabilitate Europe or have you graciously invited me to be with you in the hope of rehabilitating at least one North American? In any case, you will hardly be surprised that I am going to talk this morning about human rights -- specifically, the rights of human beings who are not only deaf, but also blind.

We do not know precisely how many people fall into this unenviable category. We do know that a percentage of deaf people do become blind and that a percentage of blind people do become deaf, and that a percentage of people with normal hearing and sight do simultaneously lose both faculties through accident or meningitis or other causes. We know that in terms of effective social functioning loss of hearing with loss of sight does not equal deafness PLUS blindness, but rather deafness TIMES blindness. We know that helping such productive human beings is one of the great challenges of rehabilitation -- a challenge that after centuries of despair and neglect is at last beginning to be met. Hopefully through our meeting this morning, forces will be set in motion that may result in more progress for deaf-blind persons in the next five years than in the past fifty. Hopefully, some of the more dynamic and perceptive among you will not only comprehend the problem, but also envision workable solutions -- and begin the exciting, inspiring, professionally and humanly rewarding process of bringing those solutions into reality.

In my role as president of the Hadley School for the Blind and chairman of the Committee on Services to the Deaf-Blind of the World Council for the Welfare of the Blind I happen to be both an educator and a rehabilitator. As such, may I recommend to your consideration the definition adopted last September in New York City by the first Helen Keller World Conference on Services to Deaf-Blind Youths and Adults. The definition reads that deaf-blind individuals are "persons who have substantial visual and hearing losses such that the combination of the two causes extreme difficulty in the pursuit of educational, vocational, avocational or social goals". The key word in the definition is COMBINATION. The person with substantial visual loss can still hear and listen. The person with substantial hearing loss can still see and observe. But the person with substantial losses of both sight and hearing experiences a combination of sensory deprivation that may cause extreme difficulty in achieving life's most vital goals. Such a person is by definition deaf-blind.

The foregoing definition has the merit of being functional rather than technical. Few things could be more heartbreaking than to tell a person experiencing severe sight-hearing loss that he or she is not quite blind enough or not quite deaf enough to meet some technical requirement for help. Life is more important than any technicality!

Deaf-blindness in its extreme form means simply that one cannot see, one cannot hear, one must rely wholly and utterly on the sense of touch to communicate with one's fellow human beings. This is precisely what deaf-blindness means to me as an individual. I cannot see the brightest light, and if the atomic bomb went off under my chair this morning, I doubt that I could hear it. But deaf-blindness need not be total to present severe and special problems requiring wise and special solutions. If an individual has substantial visual loss and substantial hearing loss and the combination of the two is causing extreme difficulty in achieving an education or in securing employment or in enjoying recreation or in gaining social participation, then that individual is deaf-blind. That individual needs our help!

As to the rights of deaf-blind persons, the Helen Keller World Conference on Services to Deaf-Blind Youths and Adults unanimously adopted a declaration on this very subject. Let me read it to you now and comment on each article.

PREAMBLE - "Delegates from 30 countries around the world assembled for this first international conference on services to deaf-blind youths and adults, welcoming the United Nations Declaration of Human Rights and the Declaration of the Rights of Disabled Persons, have agreed upon and have adopted the following Declaration specifically concerning the needs and rights of deaf-blind persons and recommend it to the attention of the world community:"

ARTICLE 1 - "Every deaf-blind person is entitled to enjoy the universal rights that are guaranteed to all people by the United Nations Declaration of Human Rights and the rights provided for all disabled persons by the Declaration on the Rights of Disabled Persons."

This article simply states that deaf-blind people are human beings with the same basic rights as all other people, including all other disabled people. Who would deny it? According to one authority, a noted U.S. rehabilitation expert once described deaf-blind people as "vegetables". I don't know the expert's name, but I trust that by now the "vegetables" have planted him six feet deep.

ARTICLE 2 - "Deaf-blind persons have the right to expect that their capabilities and their aspirations to lead a normal life within the community and their ability to do so shall be recognized and respected by all governments, administrators, educational and rehabilitation personnel and the general public."

This article states that deaf-blind persons are not only human beings, but also NORMAL human beings who wish to live normal lives within the community. They expect the community to recognize both their desire and their capacity to do so. The things that make you happy or sad, make deaf-blind people happy or sad. It is as simple as that.

ARTICLE 3 - "Deaf-blind persons have the right to receive the best possible medical treatment and care for the restoration of sight and hearing and the services required to utilize remaining sight and hearing, including the provision of the most effective optical and hearing aids, speech training, when appropriate, and other forms of rehabilitation intended to secure maximum independence."

This article refers to our earlier point that deaf-blindness need not be total. In fact, every bit of residual sight and hearing should be utilized and enhanced, both through remedial medicine and modern technology. Since communication is a two-way exchange, any training that can advance a deaf-blind person's ability to speak will be tremendously helpful.

Please note that the goal sought is to increase the deaf-blind person's INDEPENDENCE.

ARTICLE 4 - "Deaf-blind persons have the right to economic security to ensure a satisfactory standard of living and the right to secure work commensurate with their capabilities and abilities or to engage in other meaningful tasks, for which the requisite education and training shall be provided."

This article could be summarized as the right to be useful - the right to work, to contribute, to feel one is giving to others as well as receiving from others. I have noted that every time a deaf-blind man or woman gains a paying job, he or she gains new respect. Money is a great equalizer! The surest passport to independence is an adequately filled pocketbook.

ARTICLE 5 - "Deaf-blind persons shall have the right to lead an independent life as an integrated member of the family and community, including the right to live on their own or to marry and raise a family. Where a deaf-blind person lives within a family, greatest possible support shall be provided to the whole family unit by the appropriate authorities. If institutional care is advisable, it shall be provided in surroundings and under such conditions that it resembles normal life as closely as possible."

Note that this article not only asserts the deaf-blind person's right to be part of a family or of a family environment, but also the right to live alone or to be head of a family. Individual desires and circumstances will vary, but the right is inherent. I have known deaf-blind persons who live happily with their parents, deaf-blind persons who are themselves successful parents, deaf-blind persons who live independently in their own apartment and others who prefer the security and comfort of a well-run institutional home. I, myself, lived alone in my own bachelor apartment for 5 years as a young man, later marrying a blind woman with normal hearing and am now the proud father of an athletic 15 year-old son who specializes in golf, baseball, and all forms of pictorial art. The right to a family life is as old as Adam and Eve.

ARTICLE 6 - "Deaf-blind persons shall have the right, and at no cost, to the services of an interpreter with whom they can communicate effectively to maintain contact with others and with the environment."

This article emphasizes the vital importance to a deaf-blind person of interpreter services as a communication link with the community. The words "at no cost" have caused some controversy, but it was the thought of the conference that many deaf-blind persons, especially children or the elderly, simply will not have personal funds with which to employ interpreters. Whether the answer lies in volunteer interpreters, interpreters supplied by private social agencies, government-employed interpreters or a combination of all three will probably depend on the philosophy and culture of each individual nation. But the right to communicate is perhaps the greatest single right for which a deaf-blind person longs. The human mind will break through any barrier to reach other human minds.

ARTICLE 7 - "Deaf-blind persons shall have the right to current news, information, reading matter and educational material in a medium and form which they can assimilate. Technical devices that could serve to this end shall be provided and research in this area shall be encouraged."

This article extends and reemphasizes the right of the deaf-blind person to information and knowledge about the world in which he lives. After all, the physical senses are merely channels through which the mind observes and communicates with the community and the environment. What really matters is the mind behind the senses. To KNOW is more important than to see; to UNDERSTAND is more important than to hear.

ARTICLE 8 - "Deaf-blind persons shall have the right to engage in leisure time recreational activities, which shall be provided for their benefit, and the right and opportunity to organize their own clubs or associations for self-improvement and social betterment."

This article draws attention to the fact that life is not all work and earnest endeavor, but should also contain a vital element of recreation and enjoyment. Having much in common, many deaf-blind people take pleasure in sharing activities with other deaf-blind persons. Mutual life enhancement is one of the great foundation stones of civilization.

ARTICLE 9 - "Deaf-blind persons shall have the right to be consulted on all matters of direct concern to them and to legal advice and protection against improper abridgement of their rights due to their disabilities."

Again and again deaf-blind people have cried out for a larger part in shaping their own destinies. The right to make one's own decisions is the basis of freedom. Like all other people, deaf-blind persons need options from which to choose, choices from which to select. Only by exercising his or her judgement can a deaf-blind person function as a fully equal citizen in the community.

And now, a final word... Through you, let me extend deaf-blind persons who can read and write English Braille, no matter where in Europe or beyond their homes may be, an invitation to study by correspondence, free of cost, with the school of which I am president - the Hadley School for the Blind, 700 Elm Street, Winnetka, Illinois 60093. Deaf-blind persons all over the world find our course called INDEPENDENT LIVING WITHOUT SIGHT AND HEARING especially helpful. Indeed, the course is now also available in an inkprint edition for study by any professional person who is working in behalf of deaf-blind people. Please write to me at the Hadley School for further information. Our goal is not only to preach rehabilitation, but also to teach it!

Colleagues and friends, every storm should have a rainbow. It is our challenge, it is our privilege, to create rainbows - or, better still, to help deaf-blind persons create their own rainbow in a world that deserves to be lived in.

EXCLUDING AND INCLUDING THE DEAF (FROM AND INTO THE FAMILY CIRCLE).

T. H. SUTCLIFFE

ABSTRACT Deafness frequently excludes from the family circle. The prelingually deaf child is excluded because of inadequate language and speech; the young adult because communication by lipreading breaks down and the reasons for failure are not understood; the deafened because the psychological effects of deafness are not understood by himself or the family; the elderly deaf because they cannot learn new techniques. It is essential that information be provided for the family (a) to assist the deaf child in acquisition of language and, rather than to reject his efforts with shame to welcome with pride; (b) to gain insight into the substitution of one sense for another and the reasons for adults failing and succeeding to lipread and to see the value of a go-between; (c) to understand the bewildering effects of deafness coming in mid-life; (d) to enable patient dealing with the elderly. Adequate information may transform the whole of family life.

T. H. SUTCLIFFE - Executive Member of The Royal National Institute for the Deaf; British Deaf Association and World Federation of the Deaf.

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INTRODUCTION In this paper we shall see that far from being exceptional, the general rule is that when members of a family converse together, the deaf member is excluded. We shall examine the reasons for this, see the necessity for adequate information in the hope that it will give insight and alter the attitude of the family. Suggestions will be made for overcoming the problem and including the deaf members into the family circle.

We shall deliberately avoid the term "integration", which often begs the question, is used too lightly and glibly, and implies that the problem is solved, when it is by no means solved. It must be remembered that however willing and anxious a deaf person is to participate in the activity of conversation, he is entirely dependent on the willingness of hearing people to cooperate and enable him to participate.

For brevity we shall use the term "deaf" rather than "hearing impaired", also for brevity, we shall deal with total, or severe deafness, when a hearing aid is of little or no value. Problems caused by a small hearing loss will then fit into their proper place.

T. H. SUTCLIFFE - Executive Member of The Royal National Institute for the Deaf; British Deaf Association and World Federation of the Deaf.

THE DEAF CHILD Let us begin with the child. A child who is severely deaf from birth, or before he acquires language, causes immense family problems and the outstanding one is communication. Long past the time a hearing child is prattling away to older members of the family, the deaf child has not uttered a word. Obviously he cannot imitate verbal sounds, which he has never heard and so speak. But the bigger problem is that he has no idea that there are such things as words, even the simplest words which refer to people and things. He will not even know his own name. It is clear that at this stage he is excluded from all verbal communication.

In this country for many years the advice given to the parents has been "Do not sign to your child. Make him watch your lips and learn to lipread and speak". This sounds to be good advice, but parents find it an exceedingly slow business. For some time the child is as unlikely to expect information from the moving lips of his mother as from the shutting of her eyes in normal blinking - both are equally soundless.

It is difficult for the normal hearing person to enter into the experience of a severely deaf child or adult. He can however do so if he is thrust into the position of watching a demonstration of moving lips without the voice being used: as I might speak silently to you now. None of you would like to sit through an hour's lecture given in that fashion.

But to return to the parents. In spite of the child being excluded from verbal communication, life must go on. They will find that their deaf child will find a way to make his wants known. For example, he may take his mother's hand, lead her to the refrigerator, point to the milk bottle and perhaps imitate the act of drinking from a glass. This series of signs will be a means of communication and his mother will act on it.

But the question arises, how is she to convey her meaning or intention to him? If, following advice, she refuses to use signs, she will exclude him from communication with the family, in a way he finds easy and useful.

It would seem essential that information should be given to the parents that in some countries there is now a big difference of opinion on the use of signs or gestures. Research has proved fairly conclusively that using signs with young children need not retard the acquisition of speech and language (1) K. Meadow. A Developmental Perspective on the Use of Manual Communication with Deaf Children - Methods of Communication RNID p.87. 1975. On the contrary in America and the Scandinavian countries, some teachers of the deaf are advocating the use of signs as a stepping stone to acquiring a knowledge of words. How does this work?

Instead of a mother abruptly picking up a child and carrying him off to bed, she might more gradually prepare him, by indicating bed. A thoughtful mother might use the well known mime of putting the hands together at the side of the head to indicate a pillow, and then resting the head upon it. A few nights repetition and the meaning would become clear to the child. By using this sign she has done three things. First she has given him a referrent, subconsciously he will understand that both of them can use this referrent for something out of sight, without having to go upstairs to point to it. Secondly, she has given him something which he can translate into a verbal form. Thirdly while formerly he was excluded from the family, now by means of communicating he is included into the family circle. This has a big psychological effect both on the child and parents, and is clearly shown by a true story frequently told by Dr. David Denton, the headmaster of the Maryland School for the Deaf. Two parents for a long time, following advice, refused to use signs. Later they changed their view. Soon after they began to sign, their little boy came back to school and in his own way said, "Mummy and Daddy are deaf now".

THE YOUNG ADULT By the time a deaf boy is 15 or 16 many parents are very disappointed at the very poor command of language he possesses. Dr. Conrad of the Department of Experimental Psychology, Oxford, by a research project found that the reading ability of deaf school leavers was exceedingly low (2) R. Conrad. The Reading Ability of Deaf School-Leavers. Br. J. Psychol. 47. 138-148. 1977. Many parents are bewildered and cannot understand why, after ten years at school, their deaf boy cannot write a correct letter, nor read newspapers and simple books, nor express himself in grammatical English. They cannot understand why he is so far behind his hearing brothers and sisters. Many parents feel ashamed of their deaf son and reject him, exclude him from the pride they have in the general educational development of their other children.

The way to alter this attitude is to inform the parents. There are 14 major difficulties in the acquisition of language caused by deafness. Many of them are obvious once stated. For example, take the indefinite and definite article "a" and "the". Through hearing countless repetitions of them the normal four year old child uses them correctly. But these two little words are almost imperceptible to lipread and so that major factor of language acquisition, repetition, is missing for the deaf. As a consequence many deaf adults omit them, or use them incorrectly, throughout life. Another example is that the slight differences in the active and passive voice are not perceived in lipreading, or are overlooked in reading the printed word. So the difference in meaning of "I was owing a hundred pounds for three months" and "I was owed a hundred pounds for three months" is not seen.

If a small book were available to parents, or even a printed leaflet were distributed by schools, the attitude of parents might be altered. With real understanding and insight they would realise that for a deaf child to acquire language calls for great perseverence and hard mental activity. No longer would there be shame, rejection, exclusion; but pride in his struggle against immense difficulties and in his achievements, and a warm welcome into family affairs.

We now come to what is the biggest exclusion from the family, which is due to the failure of lipreading in group conversation. But first we must consider why lipreading does fail. We come to what we might call the substitution of the senses.

SUBSTITUTION OF THE SENSES In everyday activities one sense cannot be a perfect substitute for another. Arriving home on a dark night, one may substitute touch in the finger tips for sight, in finding the keyhole. But one does not put the key into the lock with the same direct and precise movement, as if guided by the sense of sight. All that is in the concrete. Let us move to something invisible and intangible - sound. When deafness makes sounds of words imperceptible, we try to substitute for hearing, the sense of sight. We closely observe the movements of lips and tongue. But the result is far from perfect. The reason for this is well known, and is given in all standard text books on lipreading. It is that certain consonants, for example P, B, and M, when pronounced while quite different to the sense of hearing, are identical to the sense of sight. Also, certain consonants, T, D and N are hidden inside the mouth. So then there is much ambiguity in lipreading. The remarkable thing is that in spite of over fifty percent of the consonants being ambiguous, and so much guesswork being necessary, yet when the twelve factors involved in lipreading are all working favourably, it can be successful. Lipreading, though very imperfect, can be a most valuable thing.

But the substitution of one sense for another, sometimes is impossible; there is complete failure. A blind man cannot perceive a sunset by touch. A blind man in a factory hearing a wheel revolving at high speed would not attempt to touch it. It would be too dangerous. He cannot substitute touch for sight. Speed causes failure of the substitute sense. One of the chief factors involved in lipreading is the right tempo. If the speed of speaking is too fast lipreading is impossible. The substitute sense of sight for hearing fails altogether. The important point is this. Normal speech is usually too fast. So then while often one individual person will speak slowly to a deaf person; usually in a group, conversation proceeds at normal speed. This is too fast, and as a consequence, the deaf person fails entirely to lipread. It must be remembered that very frequently family conversation is group conversation, which means that the disability of deafness causes one member to be left out, excluded.

GROUP CONVERSATION Now turn to the family sitting round the dining room table. Here the criss cross group conversation invariably is at a speed too fast for the deaf member of the family to lipread. A well educated deaf young woman recently stated that in her teens, the loneliest times of her life were those sitting at the dining room table, when her parents, brothers and sisters were talking and roaring with laughter; and she was left out of it all - excluded. Recently in The Times newspaper it was reported that two men, who had refused to go on strike, were sent to Coventry by their work mates. For two weeks no-one spoke a word to them; and The Times pointed out the mental cruelty involved. Deaf people may indeed smile at this, when they recall that often at the dining room table, apart from asking "will you have some salt?" etc., no-one speaks a word to them, week after week throughout the years. I do not exaggerate. Too many deaf adults will tell you that this is their common experience. They are excluded from family, group conversation.

We must be fair to such a family. Mental cruelty is not intended. What are the reasons for such apparent callous treatment? There are three chief reasons. First, the family, from the time the deaf member was a child and had no speech or language, has been accustomed to him being left out. For years it was a simple fact that the deaf member could take no part in conversation at the dining table. No time was ever fixed for reassessment, or a reconsideration of the problem, and so their customary habit of exclusion continued.

Secondly, it must be recognized that if a deaf member has certain rights, so have the hearing members. Parents will probably have realized that if one individual speaks slowly and clearly to the deaf member he may lipread what is said. But when the teenage brothers and sisters sit down at the table and are bubbling over with exciting things to say, is it possible, is it feasible, and is it right for the parents to stop such exciting quick conversation and to insist that the tempo be reduced to three quarters or half speed? It would be asking too much of healthy, lively teenagers. The parents must recognize this as a fact. Thirdly, most interesting conversations begin with trivial things. For example, Mother might begin, "I met Mrs. Smith in town today when I was shopping". "Did you?" replies Father, "and how was she?" So far this does not seem worthwhile repeating for the deaf young adult who anyway is probably not very interested in Mrs. Smith. But as the conversation proceeds the others hear that Mrs. Smith had just returned from a holiday abroad and had a most exciting thing happen to her. By the end of this bit of conversation, it is an effort to go back and repeat it all for the deaf member; and so he is excluded from this interesting item. This happens far, far too often even in a family which does show concern for the deaf son or daughter.

INTERPRETING And so we come to the important question. "What is the solution to this difficult problem of group conversation, especially at the dining table?" One answer is the use of a go-between or interpreter. The family should agree that always one member should repeat in silent lip-movements, and at a slower speed, what is being said by others. This should not always be left to one person, but they should take turns. So when the teenagers are excitedly doing the talking, father or mother could interpret; when father is talking seriously on some family matter, one of the brothers or sisters could interpret. The deaf member has a good chance of lipreading successfully at this slower tempo and so being kept in touch - not excluded.

Interpreting in this way should also be done on other occasions, for example, when some of the family are sitting round the television set. Newscasters invariably speak too quickly for lipreading, and actors in a play are often participating in group conversation and speaking too quickly. The average deaf lipreader gets very little, or nothing at all ofwhat is said on television. He is generally excluded, and does not know what is happening. If one member of the family would give the gist of the news, or the plot of a play, in deliberate clear lipmovements, the deaf member would be grateful and would no longer be excluded.

Another form of interpreting should be mentioned. Many young deaf people have said, "I can lipread my mother fairly well, but I cannot lipread my father." Without going into the reason for it, it can be said that not always, but quite often, girls and women are easier to lipread than men. This leads to another factor involved in lipreading besides tempo - that is clarity. Obviously no-one can lipread a ventriloquist, yet some people have far from clear lipmovements in speaking. At present there is little knowledge about this, or how to help relatives of the deaf on how to improve their way of speaking. It would be good if serious thought were given to this question. But to come to the family problem - what is to be said if a deaf boy cannot lipread his father at all? Generally such a father has realized that he must ask one of the others to act as go-between, or interpreter. But often such a father will confine his conversation to brief remarks such as "Mary, tell John I will bring him home in the car tonight". What is over-looked is that the deaf son, John, would welcome much more satisfactory conversation with his father than brief remarks of that nature. It calls for a little effort for a father to call his daughter and ask her to repeat, while he endeavours to talk to his deaf son in a really worthwhile conversation. But unless he does so he excludes his son from paternal close contact, fellowship and advice.

One kind of interpreting may be unwanted by a deaf person. In some families one member and often a sister has taken it on herself to help by frequent interpreting, but has gone to the extreme of appointing herself an official interpreter. By that I mean that she will accompany her deaf brother (or sister) on occasions such as an interview with the doctor, solicitor or for some business matter. This family interpreter may be most helpful and the deaf member may be most grateful for help. But things can be quite different. Such a family interpreter may make bad mistakes. She may monopolise the conversation, not give the full facts, make decisions for the deaf brother and treat him in a paternalistic way throughout. There are two solutions to this problem. The deaf person could refuse help from a member of his family in this way and turn to a professional interpreter for the deaf to meet his requirements; or he could give information to his sister on the correct rules of professional interpreting and proper conduct. If she were willing to accept and act on such information, she would be of great benefit to her deaf brother. Here again we see the need for well produced information to be available.

From what we have said in this part of the paper, it will be obvious that a number of problems call for description and explanation. Even if the deaf member were capable of explaining the situation and describing his feelings of exclusion, he is unlikely to do that. It may seem too much like personal criticism and be resented, causing even more unwillingness to help. A young deaf adult cannot easily plead his own case. What is required is information or counsel from outside given in an impersonal manner. Possibly leaflets, or a book, might be made available for deaf young people to give to their parents. If such information were given to families and were received and acted upon, the lives of many deaf young adults would be transformed.

APPLYING PRINCIPLES TO THE HARD OF HEARING Before going on to deal with two further categories of severely deaf people, it might be well to see how certain things already said may apply to hard of hearing people.

One example is this, a child may gain much from a hearing aid and yet miss the repetition of a number of words, so reducing his known vocabulary. An instance of this is that a father of a young man said he was puzzled why at times his boy did not understand simple, well-known words such as "post", in the sense of a position at work or job. He said "I told him the other day he had been offered a "post" but he did not understand - he seemed to think I was talking about posting a letter or the post office". Information on language acquisition would have given the father proper understanding.

Take the family round the dining table. A deaf girl might with her hearing aid distinguish words at three or four feet. But at ten feet the speaker will be out of range. Clearly, she needs his remarks repeating for her, that is to say, she requires a go-between or interpreter. The family should be so informed and act accordingly.

THE DEAFENED Let us leave the severely deaf from birth, or early infancy, and turn to those who through accident or illness become totally deaf in mid-life. Whether this happens suddenly (and it can happen overnight), or gradually, it can have devastating effects. For a professional man, a doctor, a barrister and those whose work depends on easy communication of thought, it seems a calamity. But even for manual workers it can be a heavy blow indeed. Such people now find themselves excluded from easy conversation not only outside their home, but within the family circle. In a small book "Deafness Let's Face It" (Published, RNID), I have categorized 30 effects of deafness, some of them being of a psychological nature. These effects can be bewildering coming in middle life. To some, intense depression has led to suicide, or to contemplated suicide. In one case, a hearing wife, unable to understand what had happened to change her now deafened husband so radically, was led to divorce him. This shows exclusion from family life at its worst. What can be done to help?

The vital need is adequate information from knowledgeable people. In some countries, there are centres for giving information and training in coping with the difficulties of this kind of deafness. In England one such centre is at Eastbourne where deafened people are recommended to come for a two-week course and, if possible, accompanied by a relative. The value of this is obvious. Information can be given through the hearing husband, wife, or member of the family to take back to the others and so bring the deafened person into the family circle.

THE ELDERLY Finally let us turn to those gradually becoming deaf in old age. The old adage, "You cannot teach an old dog new tricks" applies to lipreading. Few elderly people possess the ability to concentrate on the continuous guesswork involved to overcome ambiguity. What can be done? Let me give a personal experience. A man of about 80 began to attend lip reading classes, which I organized. He made no headway at all. I leftthe district and lost touch for a time, but some years later, I called at his home. After being welcomed by his hearing wife and daughters, I sat down and began writing to him on a pad, and, as I am myself totally deaf, he wrote his replies to me. And so for well over an hour, we had an interesting time together. Then he wrote, "It is now April, and this is the first time I have had a satisfying and worthwhile conversation this year". And I wondered to myself "What had the family been doing for him over those three or four months?"

It should be remembered that not all verbal communication is the transference of vital information. Much of conversation is a simple, social activity - one person in pleasant verbal contact with another. Deafness can exclude from this social activity, as in this particular case. How badly this family needed information on deafness and how to deal with it.

SOME IMPORTANT INFORMATION FOR THE DEAFENED AND ELDERLY

a) A complex problem It is helpful both to the deafened person, and the family, if they face the fact that far from being a simple problem, deafness is a very complex one with subtle effects, in the sense of not being readily perceived and understood. Most people regard deafness as meaning that one cannot perceive sound as such, and it is thought of very vaguely. They do not realize that to miss hearing birdsong, or music, is a small loss compared with not hearing the human voice. This brings us to the real reason why deafness is complex. Physical disability is a physical matter. It makes it difficult to perform physical bodily movements and this can be seen and the limited results understood. To some extent this also applies to blindness. But deafness strikes at the interchange of thought. It strikes at mental activity and that, compared with the physical, is almost unlimited and hence complex.

So many people on becoming gradually or suddenly deaf are bewildered at the complexity of this thing which has happened to them. It is unknown, and its very varied effect can be frightening. What is required is some description of the sum total of the effects brought by deafness, and they can be enumerated under 30 headings. At first this will be unwelcome knowledge, but once understood the problem can be seen as a whole, and this can be reassuring and lead to acceptance both by the deaf member and his family.

b) Acceptance "Accepting deafness" is a vague phrase. What exactly do we mean by not rebelling but "accepting deafness" - or any other disability? One good definition is this, "facing reality rather than holding on to fiction". There are various reasons why deafness is more difficult to accept than other disabilities. To take but one, and that an obvious one; it is an invisible disability. A deafened man sitting reading a book appears to be normal, and he himself can forget he is deaf. But for the family to look back to the time he could hear and try and persuade themselves that he surely cannot be as bad as he seems; and for himself to hope for some magic wand to be waved and restore his hearing is not helpful. A full acceptance by him and his family based on a fair understanding is the first step towards a triumphal overcoming of some of the difficulties. One of the clear indications of acceptance is when a deaf person and the family, without any ridicule, can laugh and make jokes in a good humoured way about deafness. Would that more deaf persons and their families could do that.

c) Irritation The opposite of that attitude is irritation, and this needs careful understanding. Whereas other disabilities such as crippling, blindness, tend to produce sympathy and a desire to help, deafness tends to repel and irritate. The inability to communicate by the ordinary, easy way of hearing spoken words leads on to frustration and irritation. One has only to think of using a faulty telephone. A few minutes and one is shouting and angry. But there is this great difference from talking with a deaf person. One does not blame the person at the other end of the line, one blames the faulty 'phone. With the deaf person one does not blame the faulty organ of hearing. One blames himself for appearing to be dull or stupid.

Irritation can arise even between knowledgeable persons [illegible] especially when pressed for time. A certain deaf man and his hearing wife have on occasions lost their tempers when in a hurry, and after say three repetitions, he has not lipread some important statement. But they know how to deal with such a situation. After tempers cool they look at one another and have a good laugh, because each knows what the other is thinking, and one will probably say, "I am not irritated with you darling, but with the circumstances, and deafness in particular." That of course is the whole point - they can put the blame fairly and squarely where it belongs.

But take a family where this point has never been properly considered. Many people will have overheard in a hotel someone talking like this. "I shall be heartily thankful when we get away from Aunt Agnes. She is getting terrible. She is as deaf as a post. I cannot make her understand a thing. It irritates me beyond words", and so on. What is overlooked, and badly overlooked, is that it is the deafness which irritates; and if it irritates the hearing niece, how much more must it irritate Aunt Agnes, who has to carry this irritating deafness around with her, not for half an hour or so, but day after day and month after month. The need for proper understanding is clear.

d) The Use of the Writing Pad There are a few deaf people, as well as the majority of hearing people, who for psychological reasons, are reluctant to use a pen and writing pad. For brevity we will deal only with hearing people and make the following points which could be elaborated in a leaflet.

1) While one would be willing to write a letter to a person five miles away, one's whole experience of life goes against writing a note to a person standing five feet away. It appears to be quite unnecessary - hence reluctance.

2) One's whole experience of life is that normal speech is received and understood at a distance of a few feet, and shouted speech over many yards distance. Hence to shout at a person only a few feet away must make for perception and understanding. Intellectually one can conceive of severe or total deafness, but psychologically, one minimizes it. This needs elaborating to bring conviction and acquiescence. This applies mainly to strangers, but can actually apply to members of a family, when one is deaf.

3) Silence in modern life is a rare thing. Background music on television and films is used to fill gaps. Two people feel they must say something to each other or the silence would become embarrassing. So, if a deaf person hands to another a writing pad and pencil with a request to write something, immediately one foresees an embarrassing period of silence, and one tends to politely excuse oneself. Further, if one does begin to write one feels intensely this silence and plans to avoid it in future. A simple explanation of this and an assurance that the deaf person living in continual silence will not feel embarrassment, nor need the hearing one, will help to overcome reluctance to communicate in this way.

4) Being handed a writing pad often makes a person feel that he cannot think of a single thing to say, and with an embarrassed smile he will shake his head and hand the pad back. It should be explained that this sort of thing is a common happening, as when one is suddenly called to the telephone and asked to say just a little something to the one at the other end. But one can be told to write just anything, even if it is only "I cannot think of a single thing to write except ...." - and by that time he will have thought of something to write, and the ice will be broken, and he can proceed.

5) Many people feel that it is quite unnecessary and even futile to put into writing trivial statements. But again two points must be made, first that many interesting conversations start with trivialities about the weather. Secondly, much of conversation is not important but merely

indicating pleasant social contact. For a sixty year old man who has been deaf for ten years and cannot lipread, to be handed a pad which says "Lovely day today isn't it?" may bring a feeling that old times are back again, and he is being treated normally and, rather than being excluded, he is being brought back into the family circle.

CONCLUSION In summarizing, it can be said that deafness can exclude a deaf person from a large share in family life. The giving of vital information from outside, and of an impersonal kind, can transform the attitude of the hearing members and can transform the whole life of the deaf member.

Attempts to counsel and inform are regularly made in most countries; and here in Great Britain by our National Organizations - The Royal National Institute for the Deaf, the British Deaf Association, the British Association of the Hard of Hearing, the National Deaf Children's Society and others; along with social workers and teachers. But we must never be satisfied. Constantly we must be seeking better ways of explaining the severe effects of deafness and the grave danger of exclusion from family life. And we must show how a deaf member can, and should, be included in the fulness of normal family life.

Josette CHALUDE - Honorary Chairman of the National Association for Parents of Children with Defective Hearing (France).

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It was with gratitude that I accepted the invitation to this conference as a valuable opportunity to contribute my experience with deaf children in the family context. In this way I hope to be able to help towards better comprehension of the situations experienced, at a deep level in general, and in the majority of cases subjected to repression.

It is from this improved comprehension that in fact changes deemed necessary by the National Association for the parents of deaf children in France may spring in respect of the art of "taking charge" of the family, since this experience, infinitely variable from one family to the next, bears on the handicapped child's stage one teaching, development and entire future.

I shall first briefly mention the role of education, which is intended to provide the deaf child with a means of oral communication and language, i.e. with the tool for his integration into society. I shall attempt to point out the difficulties of this undertaking, the parents' role, or at least the role which they should play, the handicaps of the family itself, and finally some simple hypotheses, in order to increase the help we can give the parents.

THE ROLE OF EDUCATION : COMMUNICATION WITH THE WORLD AND ACCESS TO CULTURE

What is the role of education for a deaf child? We all know that very early deafness prevents the acquisition of speech and language. In the case of children with normal hearing the foundations of these skills are formed in the cradle and develop by means of permanent interaction in terms of communication between the child and his surroundings. There is no point in stressing that this communication is not only through the sense of hearing.

Meanwhile, if we wait for these processes to develop spontaneously in a deaf child, we can rightly assume that he will remain dumb. Can we demand the natural mechanisms of speech acquisition from him?

Top educationists know that we can, and the considerable help that they can expect nowadays from early use of good quality hearing aids only serves to make them more optimistic.

Even before such technical progress, sufferers of deafness showed that their assumed handicaps could be overcome through their ease of acquiring spontaneous language, including speech.

However, the term "deaf mute" has not become obsolete. Removing it from school facades would in most cases constitute an act of kindness rather than a true representation of circumstances.

As we have seen, the education of a deaf person is a gamble.
What makes it different from other handicaps is that the prognosis is never clear. Within the same hearing defect, a young deaf person may, depending on his education, remain deaf mute, marginal and without self-sufficiency, whilst another may become an engineer and will need nothing more than a go-between for telephone conversations.

The ROLE of education is therefore considerable. It alone explains the passions, pressures and polemics across the whole educational system, in which the parents are naturally involved. In a nutshell it explains both the parents' responsibility and their militancy.

RECOGNITION OF THE PARENTAL ROLE

I shall not maintain here that the parental capacities alone determine the future of a deaf child. The quality of education from which he benefits additionally, i.e. the technological aids and stage one teaching techniques or methods play an equally large part.

In the last ten years or so however, two situations have imposed a new, special educational approach on practitioners: they may no longer consider the child apart from his family context.

- On the one hand, the diagnosis made in the first days of life and immediate technical aids are of no use if the child's family do not fulfil their role. What other milieu can there be than his family for a three-year-old child?
- On the other hand, more and more parents and specialists are refusing to separate the child from his family, and co-education with normal children is being increasingly sought in order to permit the child to return to his family every evening.

Thus, either we must demand constant support of the child from his family, using more or less integrated methods, or we must hope for a good start in stage one education before entry to a specialised institution, but in either case, the family cannot be set apart from the educational aspect of deaf children as was systematically the case in the past.

PARENTS AND THE PROBLEMS OF THEIR ROLE IN THE DEVELOPMENT OF COMMUNICATION

Does the family have a proper understanding of the role which it can and must play in education? Are parents aware of the problems and obstacles they will encounter?

Since I have spoken with countless mothers and innumerable fathers often very intimately in order to find our their complaints, hopes and anxieties so that I can identify with them without difficulty owing to my own parental experience, since I have occasionally reconstructed situations which they themselves had difficulty in analysing, I think I can answer these questions.

At a time when the education of the deaf is being pounced on by techniques and technologists, not to mention technocrats, we must hope that their discussions will not suffocate the essentials.

Through my experience I have always stressed the importance of parents having love, faith and joy at their service. Obviously this has nothing to do with science, but I shall not hesitate to say "so much the worse for those who laugh at this".

At a pinch love is perhaps one of the lesser requirements, but it does help. On the other hand faith and joy are basic. What we are concerned with is starting communication, wanting to communicate, inducing and developing communication. The following are essential:

- there must be no blockage or inhibitions;
- the tools given to natural teachers in the form of information and advice must truly aid them, i.e. it must be ensured that those receiving them are capable of making use of them.

Success in stage one education of a deaf child under dynamic conditions requires considerable energy. The investment is one which will have to continue for years and years, especially of course if the child is not institutionalised. Where will this energy come from if not desire? Where does the desire come from if not from hope and faith? How will it develop if not from the joy of success, continuous creation and self transcendency?

Joy is essential in teaching a deaf child. Since he is deprived of the normal means of understanding what goes on around him he has only his sight to assess a situation and the feelings he inspires, what is expected of him, and the behaviour most likely to make him loved and esteemed by his parents and family. An expressionless face, severe eyes, systematic refusal to adopt his method of communication, an irritated attitude and anger for which he cannot see the reason, will break the thread. This thread must however be woven, knotted and consolidated without respite by means of a permanent game, translating what is experienced, felt, desired, understood etc. into a linguistic code. This is only possible if one has joy, hope and pride.

Evidently then, unshakeable faith is necessary to persevere for years and years, whilst thousands of educational tactics were required to produce the first spontaneous words.

Whether we wish to express a wish orally, to correct voice production or merely to have a command obeyed, as with any child, the deaf child must at least have the feeling, conveyed by the parents' and family's attitude, that his efforts are productive, that he is not the victim of injustice or arbitrary demands, that he is understood and that he is not rejected or despised.

The whole family art will consist of showing the greatest closeness, never departing from an attitude which gives the child a sense of complete security. This does not seem much, but the adult is so easily mistaken when faced with children's behaviour! A fortiori when communication is difficult. We must realise how much patience, watchfulness, quiet firmness, intuition, and how many small and great sacrifices are necessary for this.

From his first few months, and in later years, the child needs surroundings in which people are constantly watching out for opportunities to communicate in a highly demonstrative manner thus creating the desire to understand and, later, to talk. Recently a remarkable father said to me, "In front of our deaf child we are mimes and clowns". Mimes and clowns, obviously, who talk without stopping!

Entering into communication with a deaf child is literally giving yourself to him. Those who imagine that the effort must come from him are very mistaken. To be sure, the deaf child makes tremendous efforts, but he makes them only insofar as he is brought to do so, and insofar as his successes are appreciated. It is the adult who must do all the work. He must pounce on every opportunity to develop an appetite for language and the capacities for comprehension and self-expression. He must be available to respond to the child's every demand. He must be creative in order to create these opportunities and bring not only the family but even young playmates, neighbours and tradespeople in the neighbourhood into the game. He must not be ashamed of his child's inadequacy in the use of speech and language, or at any rate he must not show it but must be proud of his child's progress and show that he is proud.

The adult must be firm in order not to encourage unruliness and to stem the characteristic behaviour which in so many deaf children becomes a means of expression which it is fatal to become involved in. However, he must not confuse the naughtiness of a spoilt child with the suffering of a frustrated one.

Through his approach it is the adult who helps the child to develop his will and ambitions at the same time as his aptitudes, and it is obviously the adult who may or may not make him believe that he can or must ask for help from others all his life.

A GLIMPSE AT PARENTS' EXPERIENCE

In terms of these educational necessities and material and psychological limitations, what is the real situation? Evidently the one which is known to all the families. It would be a truism to say that the handicapped child is simply an indicator who suddenly points out both untapped potential and weaknesses in people and in the family group.

We do not see what is going on on the roof-tops. However, I shall invite you to think about some simple exclamations or complaints made by parents. These generally come to see us with quite precise wishes whilst unconsciously looking for a dialogue opportunity. When they learn that they are dealing with parents who like them are raising or have raised a deaf child, confidences come naturally.

Here are just a few, chosen from amongst hundreds:

A father: From the day I learned that my little boy was deaf, I have never slept without taking sleeping pills. That has been for twenty years.

A mother: My husband bought a dog's lead for our kid. Now that he is stronger than his father you can imagine who leads who.

A father: My wife is suffering from nervous depression for the fifth time. It's all because of the child.

A mother: I shall never forgive my husband for making me send my boy away at the age of three, but he would have left me, and I've got four other children.

A father: It's a fact that for years I've always arranged to travel in a separate railway compartment from my wife and deaf child.

A mother: When my husband gets home at the same time as my daughter and me, he waits on the street corner until we have gone in so that no-one will see us together.

A mother: None of my sons ever wanted to take their little deaf sister to the pictures, and when we had anyone in to dinner my daughter was told either not to open her mouth or to go and eat in the kitchen.

A young deaf woman psychologist: My parents lived parallel lives. My mother was a doctor and gave up her career for me. They will never recover from the sacrifices they must have made to bring me up.

As for the militant who founded the association with me, twelve years ago she told me: "When parents do not get divorced I take off my hat to them".

These comments enable us to get a good glimpse of family dramas. In fact, it is not easy to help the parents of a young deaf child since their life must be lived in confusion, with them powerless to identify their problems, and to objectify their feelings and reactions. It is difficult for them to recognise simply that they are in straitened circumstances. In the majority of cases it does not occur to them to consult somebody and seek help.

SOME SOCIAL AND CULTURAL FACTS

Deafness cannot be seen. However the fact that a child understands nothing, or only with difficulty, that he expresses himself in an odd manner, with an often unattractive voice, that he uses a vocabulary and syntax giving him the appearance of a child suffering from mental weakness or behavioural disturbance - all this creates in parents feelings of embarrassment, shame, even rejection, difficult to control. Whether overcome or not, hidden or not, these feelings almost always exist.

The same phenomena exist in the case of brothers and sisters. The difficulties encountered by these are among the most repressed and the least known, mainly because nobody invites children's opinions. Such difficulties are nevertheless very important to them.

I think I have noted certain convergences, although there is no set rule: for instance that a deaf child from a relatively high socio-economic class is doubly handicapped, due to the family's reactions to his difficulties and inadequacies. Having a father who is a surgeon, a bishop for an uncle, brothers and sisters pursuing courses of higher education, these are not necessarily advantages if the psychological problems are not overcome. It is much easier for a labourer to permit his child to have a future as a labourer or mere white collar worker than for a father who is a minister. We have no minister fathers amongst our members, nevertheless we ought to.

I have also observed significant differences in the behaviour of fathers and mothers. It is not so surprising that approximately two out of three of our members have female militancy as their driving force. In general, in parent-teacher associations, men are in an overwhelming majority.

This issue seems mainly a cultural one to me. Furthermore these differences appear to me to be lesser in young families, in which the roles are more balanced. Here the father does not despise educational tasks, and even takes his share of the problems the children cause. Injured paternal narcissism, rife among certain Mediterranean fathers in my opinion, becomes more bearable in a society which little by little is acquiring greater tolerance towards those who appear "different".

However, in spite of this favourable progress, the parents, either one or both, repress "rejection" type feelings. This repression is so strong that this simple word incites protests in a journal or conference.

These, then, are the subtle mechanisms which in so many cases take the form of rejection of the handicap, its consequences and its stigmas: technical aids, sign language and frequenting deaf people's communities. I shall return to this.

What is behind all this? Answer - feelings, feelings and again feelings. Anxiety about the cause of the handicap, which is rarely completely certain, anxiety for possible responsibility, anxiety about ignorance in terms of the possibilities for rehabilitation and for the social future. Parents have both unjustified fears and impossible hopes. They are anxious about decisions they have to take. The right solution is not always at hand nor found at the first attempt, whether the parents have been badly guided, or, simply, whether they have lacked confidence and run from one doctor to another, with the wild idea that the diagnosis was wrong, or even that there is a miracle cure.

The most contradictory fears and desires are found in the family in often pathogenic situations, which compromise the whole future not only of the deaf child but of the whole family.

It is not easy to involve the whole family in an approach which has both a very voluntary nature and a very natural one. It is important that there must be a certain polarisation on the deaf child, but at the same time no member of the family must feel frustrated at losing some of the attention of others. This is easy to say, but often the parent who comes to take matters most in hand must struggle on several accounts and the family atmosphere rapidly suffers.

Most of you will know the play "A day in the life of Joe Egg". During a debate which followed this play, I found that the parents of maladjusted children had seen another play than I had: the destruction of the couple's sex life, so obvious, was not raised by anybody, and I provoked indignant amazement when I suggested this analysis. From this I was able to measure the force of repression in matters which our culture has taught us to consider as unworthy and hardly to be acknowledged. It is still to early to make fun of Freud.

Who will dare to admit to himself for example that he or she has or has had murderous impulses towards his or her child? However, although we cannot extract confidences in this respect, it is not rare to hear a sort of admission uttered: "I have sometimes felt that too".

COPING WITH "UNSPOKEN OF" SITUATIONS

In order to take into account the difficulties of a family raising a deaf child, one of the greatest difficulties is that what is most important goes to the level of "the unspoken":

- i.e. lack of communication from parents in respect of their perception of the child and the handicap; silence on the social isolation in which the parents are put or to which they condemn themselves by refusing to subject their child to the stare of others; silence from the father in respect of his narcissistic trauma and from the husband about his frustrations owing to the preponderant attention his wife gives the child (it obviously does happen that the father becomes even more involved, and it is the wife who is neglected); silence from brothers and sisters about feelings of jealousy, aggression and suffering caused by an impression of unfairness, so easily born behind the most favourable appearences; finally silence about transferring the child to the specialist, as so often happens, and which leads to unconscious rejections of the advice which even if good is literally not heard.

RETHINKING EDUCATIONAL PROJECTS FOR THE DEAF CHILD

I feel most strongly that the approach to the deaf child through the family should be completely and radically changed. In this respect we are suffering from excessive speed of evolution, and from the burdens which are always felt as soon as we pass from the qualitative to the quantitative, or try to extrapolate individual conditions, even if significant, from mass education.

First stage teaching techniques have certainly progressed a long way in the last ten years, as well as technical aids, which are more reliable, and when applied in the first few months modify the conditions of their application quite fundamentally.

In France the authorities have made a tremendous effort. In future, most parents will have the possibility of being rapidly guided in terms of the specialised structures of diagnostics and care. However, I am not afraid to say that this is not enough.

The French system suffers from a serious defect: it is divided. This is the case in issues as essential as the following ones:

- is it in the interest of the deaf child to be brought up in and by his family, or to be sent away to be looked after by educationists and specialised teachers?

- is it preferable for him to adapt as an individual to the maximum in the society of us, who are present here, in which he will be required to develop, or is it better to prepare him for a fate based on integratiǒn into the deaf community?

- must his parents and teachers aim most of all to help him earn his living, or must they sacrifice all for his personal development?
- must he learn sign language, or avoid using it?

The gamble of speech - which is that of the parents of my association but also that of adult deaf people - means that some will fall into the "speech trap": the fear of contagion from sign language, which, owing to its simplicity for the deaf person, prevents sufficient practice of oral communication (sometimes a justified fear) i.e. parents are pushed into behaviour which is unbelievably inhibiting to communication.

In a parallel way, in order to re-establish sign language, the usefulness of which cannot be denied, a demobilisation campaign is arising in France: at a pinch, since the deaf are mute, they would only remain mute. At UNESCO, I have heard the term "parental terrorism" used in front of me for efforts made by families to make their child learn oral communication.

I find these over-simplifying analyses deplorable, which add cruel uncertainty to the parents' anxiety and make them almost inevitably feel guilty, since, to all appearances these various projects for deaf children cannot, in all cases should not, exclude each other, a priori.

I find it deplorable that the world of the professionals is dragging the parents into the enclosed arena of their band-wagons. It would be more honest to ask ourselves about facts which make our certainties questionable.

Somebody very rightly said, at our congress on parental guidance, that "the manner of informing the parents of the diagnosis is already an act of guidance". What realities are hidden behind this attestation?

Why is it that certain working class or agricultural families, of low socio-economic status, with a certain lack of material means, have achieved results sometimes more often and better than others who seem more privileged, however little they have benefited from the required time of those who can give them advice?

How can we explain that certain highly competent specialists sometimes induce parental behaviour which is prejudicial to the development of communication, whereas others are deemed rather to induce positive changes, without these facts being able to be connected with significant cultural differences between parents?

However necessary it may be, it seems that technical answers alone are not sufficient. Up to now, the essential has not been found in institutions. The essential lies in the development of responsibility, freedom, information and dialogue. Without these, we can only transfer the problem of educating the deaf, whereas it needs radical change.

Certain work has shown us the way. Canadian teams have shown that decisive help may be given to the parents of a small deaf child through immediate contact with more experienced parents who also have the requisite maturity. Real co-operation has started in this spirit between professional teams and teams of parents.

Our own comments fully confirm this Canadian report. For a long time my association has considered irreplaceable the possibility of young parents consulting people, obviously competent people, with whom they can identify and establish trusting, intimate and long-term dialogue. This is a remarkable way of helping them to live through the first difficult months whilst permitting them to express all their anxieties and to obtain answers to their countless questions. Once calmed and better armed, they may more rapidly prepare the way for true educational dynamism, avoid certain pathological developments in family relations and profit more definitely from the work and advice of the specialised team. This is not a charismatic illusion: the facts are available.

Our western countries are fairly rich, especially in grey matter, and also in militant energy, so that we do not have to be resigned to two types of education for the handicapped: that of the privileged, and that of the rest. Technique has everything to gain when taking human problems into account. I hope that my modest evidence will help this to be seen.

Paris, September 8th 1978.

MOBILITY NEEDS OF DISABLED PEOPLE IN THE UK - A FORMAL SAMPLE SURVEY

Richard Gormley and Larry Walters

Abstract: 608 disabled people dispersed throughout UK with a wide range of types and degrees of disability. Self completion questionnaires analysed by computer. Sampling and questionnaire design based on reply paid "Screener" mailed to 6,950 disabled individuals, and extensive desk research. Results available in great detail.

... moving around - type of trip, frequency, duration, distance, at work, at home, leisure etc.
... use of mobility aids - particularly electric wheelchairs, satisfactory and unsatisfactory aspects.
... finance and administration - sources of funds, amounts, information required.
... social factors

Concludes UK disabled are still severely restricted in terms of mobility, finance and information on mobility aids. Some recent product developments make a useful contribution to helping the disabled with mobility problems. The "image" of disabled people amongst the general public has improved greatly.

A great deal of help with administration and data processing was provided by Mr. M. Warren of Research Services Ltd., who carried out final questionnaire layout and produced headed computer tables. The study was funded by the Lucas CAV Electrical Equipment Business in collaboration with other Lucas Group Operating Businesses, including Lucas Batteries, Lucas Research Centre, Rists Wires' and Cables and Siba Electric. This survey could never have been undertaken without the important contribution which was made by all the disabled people who so kindly agreed to take part. The authors are very concious of the amount of time and effort which went into completing the questionnaires. During the course of the survey, many informative discussions took place with members of staff of the DHSS, Hospitals, Local Authorities and organisations for disabled people. Their valuable advice and assistance was much appreciated.

1. INTRODUCTION

This paper is concerned with an application of commercial market research techniques to provide detailed, comprehensive statistics on the mobility problems of disabled people in the UK.

A great deal of published material and previous studies,* such as the Ameila Harris report, 1971, "The Chronic Sick and Handicapped in Salford" by Dr.T.Fryers, and the survey of wheelchair users conducted several years ago by David Fenwick of OPCS and published recently were reviewed. The authors were unable to obtain from those sources up to date, comprehensive statistics on usage of all types of mobility aids. We were also unable to identify in detail factors such as finance and availability of product information consistent with changes in usage patterns - primarily increases in the use of specified classes of mobility aids such as occupant controlled, indoor/outdoor electric wheelchairs. Accordingly, the intent of this study is to provide that detailed picture, and help forecasts of the numbers of mobility aids of different types that will be needed over the next few years.

The task of market research is to establish distributions of features across a large group. It does not provide data which is absolutely correct when applied to an individual. The new comer to this field should also be made aware of the practical conditions which exist. From the market researcher's point of view, for example, studies often have to be completed within a planned period of time and to an agreed budget. Sample size, interview methods and other features therefore require careful planning. Similarly , the research user has to accommodate results which are usually expressed as probabilities rather than certainties. This study attempts to establish within that framework a wealth of detailed information which was not previously available, and to point to the balance of evidence in favour of its conclusions. The authors suggest the interested reader should weigh the information against his own sources and views and invite further discussion which could involve more detailed examination of the computer tabulations on which the paper is based.

2. OBJECTIVES

Thissurvey of disabled people was designed to obtain information** about the mobility problems of disabled people.

Specifically, we compared the responses of three matched groups of disabled individuals to 87 questions covering:-

(1) ... patterns of mobility - to and from work, trips outside the home, common activities in the home, leisure time activities.
(2) ... usage of mobility aids, particularly electric wheelchairs.
(3) ... sources of information on mobility aids - printed sources and people who gave advice and information.

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* See Appendix : References and Organisations.

** In addition, detailed objectives for Lucas' financial policy, marketing activities and product design and development were specified.

(4) ... satisfactions and dissatisfactions about mobility aids, wheelchairs and components, particularly the joy stick controller.
(5) ... financial conditions affecting supply of mobility aids.
(6) ... social factors affecting the use of mobility aids such as electric wheelchairs.

The three groups were disabled people who currently use electric wheelchairs, disabled people who have never used electric wheelchairs and disabled people who have used electric wheelchairs in the past, but do not now use them.

3. SUMMARY OF CONCLUSIONS

1. Disabled people go out infrequently, for short periods, and the types of trip they do make are largely restricted to essential shopping, and visiting friends and relatives. Indoor mobility patterns are also severely limited in comparison with the general public. Many disabled are unable to carry out simple activities within the home such as "making the beds," "washing clothes" or "cooking/preparing meals." There is a serious need for continuing development of all devices and methods for improving the mobility of disabled people, both in the home and outside it. Those devices should make full use of all relevant modern technology.

2. Information resources in the UK are poorly developed. Many disabled people who have to look for facts about mobility aids are not sure exactly what information they need, or where it can reliably be obtained. The sources most frequently found to be useful by disabled individuals are friends and relatives, and their own disablement organisations. Government funded sources such as DHSS brochures and booklets, health visitors, social workers and family doctors are effective in an alarmingly small proportion of cases. There is an increasing need for a national, disinterested organisation to speak with one voice in detail to all disabled people about all types of mobility aids, not just those favoured by Government.

That requirement for the whole of the country cannot be met by existing organisations with the present facilities and financial resources. There is an urgent need for more Aid Centres and for an organisation which has a function comparable to that fulfilled by the Consumers' Association for the general public.

3. Disabled peoples' incomes are still on average, low. Total weekly income from all sources to complete households containing disabled individuals are roughly equivalent to the weekly average pay of one member of the national workforce. Insufficient extra resources are available to disabled people to meet added costs of mobility and other needs essential to normal life. For example, 45% of disabled people have spent money which did not come from government, charities or any other "free" source on mobility aids. The ability to lead an independant life, and spend moderate sums on personal interests, which usually involve moving around, is still not possible for many disabled people. This picture of continuing financial difficulty was confirmed recently by the impressive EIU survey.*

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* See Appendix: References and Organisations.

4. There is a favourable balance of opinion about the technical performance of modern devices to aid mobility, such as electric wheelchairs. For example, of those who had seen joystick controllers on electric wheelchairs 72% gave positive comments and 34% were able to identify disadvantages.

5. Very few disabled people made any reference to the 1970 Chronically Sick and Disabled Persons Act. However, considerable evidence of improved relations between disabled people and the general public was uncovered by this study. Detailed statistics indicate there is both increasing contact between the two groups, and an improved level of mutual acceptance.

4. METHOD OUTLINE

(a) Preliminary Work

Interviews were carried out with 16 experts on UK disabled people. Existing information from published sources and, where available, previously unpublished statistical information was analysed. Based on that work a preliminary report was written, and specifications developed for the sample survey of UK disabled individuals. Those specifications included the sampling frame (i.e. setting target numbers of individuals in each age and type of disability group to ensure that the sample of questionnaires entering the final computer analysis stage was an adequate cross section of the total UK disabled population), and questionnaire design.

(b) Questionnaire Development

Pilot interviews were conducted with a half dozen disabled people. To ensure maximum feedback, those interviews were carried out face to face, although the questionnaire is designed for self-completion. Adjustments were made to the draft questionnaire, and it was handed over to a market research supply company for editing, coding for computer analysis and final layout/printing.

(c) Sampling

Contacts established during the preliminary programme of interviews with experts were approached with a view to listing names and addresses of disabled individuals to meet the target sampling frame of 600 completed interviews. Those approached were enthusiastic and co-operative. In general however, release of names and addresses is not consistent with the tradition of organisations concerned with the disabled, without the individuals' prior consent. Accordingly, we supplied reply paid Screener Cards to the thirteen organisations listed in the Appendix, and in total 6,950 Screeners were mailed out. Administrative and postage costs were met by Lucas CAV, and donations were also made as appropriate. The Screener operation provided over 1,500 legible names and addresses of disabled individuals which we could then contact directly. The 21% response is low. Reasons include screeners which, due to administrative delays were not received by the disabled individuals themselves, or were received too late, inaccurate/out of date primary lists*, reluctance of disabled individuals to take part in the survey and membership of disabled individuals amongst two or more participating organisations.

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* i.e. membership lists, etc. held by participating organisations.

There was a substantial proportion in favour of the self-completion interview method. Of those who replied to the Screener, 1200 were mailed the Main Questionnaire. Although the latter was an eight page document requiring several hours to complete, the response rate we now achieved was very satisfactory. Of the approximately 900 Main Questionnaires which were returned 608 were selected to complete the sampling frame for computer analysis.

The authors do not contend that this study is based on a strict probability sample. Most sophisticated statistical tests are therefore inappropriate. There is an element of self selection in the sample, and individuals who are generally unreceptive to taking part in surveys or are physically restricted from doing so are probably under-represented. However the final sample of 608 individuals conforms to the original sampling frame, and all relevant groups in terms of age, sex, income and type of main disability are included. It is therefore possible to make reasonable generalisations to the total UK disabled population.

(d) Analysis

The majority of questions are open-ended. They were coded by reviewing a verbatim listing of answers for each question, and constructing categories to account for as much of the verbatim material as possible. Close-ended questions were pre-coded on the questionnaire. Over 130 headed computer tables were produced. This paper is based on those tables and further hand analysis.

5. RESULTS

(a) Restricted patterns of Mobility.

One in three of the total sample, and one in four of current electric wheelchair users leave their homes to go to work. In terms of other types of trip, over half the total sample mentioned "shopping" or "visiting friends/relatives" first when asked what types of trip they make most often outside their homes. The next most frequently mentioned types of trip were "theatres/other public places" (17% of the total sample), and "clubs/centres for the disabled" (13%). Table A below also shows that 17% of our sample didn't know what trip they take most frequently. It is likely a large proportion of those respondents do not make trips outside the home. The distribution shown in the table is different from that for the general public, and indicates a lower level of mobility.

TABLE A: TYPES OF TRIP MADE MOST OFTEN - 1ST MENTION

BASE	608		BASE	608	
	No.	%		No.	%
Shopping.	333	55	Swimming/walking	34	6
Visiting friends/ relatives.	311	51	Car outings	34	6
Theatres/other public places.	106	17	Adult education	30	5
Club/centres for the disabled.	82	13	Watching sports	14	2
Club/centres (other)	66	11	Hairdressers	12	2
Church	57	9	Library	11	2
Doctor/hospital/clinic	57	9	Outings/trips with children	8	1
Teaching/voluntary work	47	8	Other	97	16
			Don't know/no answer	3	1

The restrictions on trips outside the home suffered by disabled people are put into even sharper focus by Table B, below, which shows that whatever type of trip is made most often, it is made infrequently and is of short duration relative to the general public. Again, including those who seldom if ever go out, about half the total sample take their "most often" trip once a week or less often. For 54% of the total sample the "most often" trip lasts thirty minutes or less.

TABLE B: NUMBER OF TRIPS AND LENGTH OF TIME

Frequency of "Most Often" Trip	BASE 608 No.	%	Average Length of "Most Often" Trip	BASE 608 No.	%
Less than 1/week	25	4	0-10 minutes	86	14
1/week	253	42	11-20 minutes	149	25
2/week	126	21	21-30 minutes	93	15
3/week	59	10	31-45 minutes	54	9
4-5/week	41	7	46-60 minutes	62	10
6/week or more			61 minutes or more	80	12

Table C shows a different pattern of moving around inside the home from that obtaining for the UK general public. For example, only 20% of our sample go up or down stairs, while the comparable figure from a general public survey is 94%. Of those disabled people who do not go up and down stairs, over half are unable to do so. This restricted pattern of activity spans a large range in terms of age, income and degree of disability.

TABLE C: ACTIVITIES IN A TYPICAL DAY SPENT AT HOME

	BASE	YES %	NOT ABLE %	NOT APPLICABLE %	DK/NA %
Leave one room to go to another.	608	93	4	1	2
Go up or down stairs.	608	20	41	28	12
Cook prepare meals.	608	30	38	20	11
Make the bed (s).	608	18	51	19	12
Wash clothes.	608	20	45	23	12
Dust/clean - house flat.	608	17	47	25	11
Go into the garden.	608	61	22	10	8

(b) Poor Use of Information Resources

Regular publications of voluntary organisations formed by the disabled themselves appear to be more important than institutional sources of information about mobility aids.

At least 80% of our total sample mentioned "news letters" of the disablement organisations, and nearly three quarters of those respondents said that source was the most useful. In comparison 7% of the total sample said "DHSS brochures and booklets" were most useful in obtaining information about mobility requirements.

In terms of people who give information on mobility aids, disabled people rely more heavily on friends, relatives, manufacturers and the ALAC's than they do on health visitors, social workers, physiotherapists or even their family doctor. Disabled individuals are unsure what information they need. For example, nearly half our sample replied "don't know" or gave uncoded (vague) answers when asked what they would need to know before obtaining an electric wheelchair. Less than 10% mentioned information such as ability to climb kerbs, ability to cope with slopes, speed, or the need for a home trial. In terms of where they expected to get information, nearly 70% mentioned manufacturers. The next most frequently mentioned expected sources were "Aids Centres" (56% of the total sample) and "DHSS/ALAC" (54%). Only 15% mentioned their doctor or G.P. and only 24% "hospital or clinic".

(c) Extra Financial Burden

Inspite of well publicised intentions to help the UK disabled population to obtain aids needed for improving mobility, over half our sample had used their own financial resources to buy mobility aids. For 87 respondents the aids obtained by those methods had cost £500 or more. Table D below also shows where these extra expenses which fall on disabled people are met. The proportion who used their "own income/saving" approaches half. Table E shows the distribution of the total household income for the total sample including where appropriate spouse' earnings, pensions, payments by govern- and the like and before tax and deductions. The average is about £75 per week. That total income to a household with a disabled person is comparable with the average weekly gross amount of £73 per person employed for salaried and manual workers amongst the general public.

TABLE D: WHERE PERSONAL FUNDS SPENT ON MOBILITY AIDS OBTAINED

BASE: THOSE ANSWERING	312	
	No.	%
Own income/savings	134	43
Family	59	19
Charity disablement organisation	43	14
Spouse	11	4
Pension	10	3
Friends	6	2
Other	31	10
Don't know	18	13

TABLE E: WEEKLY INCOME - HOUSEHOULD GROSS TOTAL

BASE THOSE ANSWERING	576	
£/WEEK	No.	%
0-20	36	6
21-30	46	8
31-40	77	14
41-50	63	11
51-60	45	8
61-70	45	8
71-80	45	7
81-90	37	6
91-100	30	5
101-120	42	7
121-150	40	7

(cont. page 8)

Continuation of Table E:

£/WEEK	No.	%
151-200	25	4
201- +	29	5

AVERAGE = £75/Week

Lack of funds was also indicated by answers to a hypothetical question which asked our sample to imagine they had substantial extra discretionary income. Almost all respondents had definite ideas on which items to aid mobility the extra money would be spent. Nearly half of the total sample said it would be spent on running aprivate car and a further 26% mentioned purchase of an electric wheelchair. Other items mentioned were "taxis" (12% of the total sample), "other special aids" (2%) and "public transport" (1%). The answers to another question in the area of finance indicate 75% of the total sample reject outright purchase of aids such as electric wheelchairs (in comparison with other purchase methods) because they cannot afford that method.

(d) Acceptability of Modern Mobility Aids

In terms of the performance and the technical features of mobility aids experienced by our sample of disabled people, the level of criticism was surprisingly low. Although most aids were covered, from walking frames to the government's invalid car or "trike," from shoulder crutches to DHSS attendant controlled electric wheelchairs, the focus of our study was on self-drive electric wheelchairs. Answers in that area showed a favourable balance between positive and negative experiences and opinion. For example, Table F, shows 27% of those who have/had an electric wheelchair mentioned "increased mobility," and 16% said their most recent chair has the advantage of high "manoeuverability." Many other advantages were mentioned such as "easy to control," "folding/transportation" and increased "independence"

TABLE F: ADVANTAGES AND DISADVANTAGES OF MOST RECENTLY ACQUIRED ELECTRIC WHEELCHAIR

BASE THOSE WHO HAVE/HAD AN ELECTRIC WHEELCHAIR - 331

Advantages	No.	%
Increased mobility	89	27
Manoeuverability	53	16
Easy to control	46	14
Folds up/easily transported	42	13
Independence	40	12
Comfort	38	11
Good over slopes/ rough ground	33	11
Speed/gears/good drive system	28	8
Easy to get into/use	24	7
Reliable/robust	18	5
Good range/batteries	13	4
Smooth ride/stable	8	2
Attractive/smart	7	2
No advantages	8	2

BASE: THOSE WHO HAVE/HAD AN ELECTRIC WHEELCHAIR - 331

Disadvantages	No.	%
Problems with batteries	48	15
Too large/clumsy indoors	47	14
Cannot climb kerbs	43	13
Battery life not sufficient	39	12
Heavy/difficult to fold/ transport	35	11
Slow	32	10
Uncomfortable	29	9
Difficult to control	22	7
Unreliable	21	6
Problems with repairs/ servicing	12	4
Movement too jerky	12	4
No brakes for parking	6	2
Expensive	6	2

(cont. page 9)

Continuation of Table F:

Advantages	No.	%	Disadvantages	No.	%
Don't know/no answer	38	11	Needs battery charge indicator	8	2
			Limited range	8	2
			Cannot disengate motor	6	2
			Other	2	1
			Don't know/no answer	50	15

Based on the total sample of 608 disabled people, nine miles was given as the average distance an electric wheelchair should be expected to travel on one battery charge. Again manufacturers' current products conform to that requirement (although there are technical reasons why batteries should not be run until fully discharged).

A special interest of our company is twin motor speed, or "joystick" controllers for battery powered wheelchairs - a field in which we have carried out pioneering research and development work over the past ten years. Table G, below, shows although more work needs to be done on the integration of control offered by the device, the balance of opinion seems to favour joystick controllers. Only 23% of the total sample gave disadvantages when asked about the controllers. The comparable figure for those giving advantages is 50%. The advantages mentioned most frequently were to do with ease of operation of the chair brought about by the controller even with weak or limited hand or arm movements. Other advantages include "simplicity of operation" (mentioned by 32% of those who gave advantages for the joystick controller), "leaves other hand free" (29%) and increased mobility (21%).

TABLE G: ADVANTAGES/DISADVANTAGES - JOY-STICK CONTROLLER

BASE: THOSE MENTIONING ADVANTAGES			BASE: THOSE MENTIONING DISADVANTAGES		
	301			141	
	No.	%		No.	%
Easy even with weak hand/arm	125	42	Vulnerable to error	50	35
Easy to operate (unspec)	103	34	Unpredictable	21	15
Does not need much effort	42	14	Not for severly disabled	21	15
Simple to operate	32	11	Not in best position	20	14
Leaves other hand free	29	10	Control not precise enough	20	14
Easier to move chair	24	8	Does not brake quickly	8	6
Increased manoverability	21	7	Dangerous	5	4
Controls in one place	13	4	Difficult to operate	6	4
Easy to learn to operate	12	4	Bulky awkward	4	3
Smooth action	13	4	Complicated	3	2
Neat	8	3	Not enough control/ speed control	3	2
Easily adopted (eg. mouth control)	7	2	Speed too extreme	1	1
Easier than tiller/ twist grip	7	2	Need separate low power	1	1
Easier to reach/get at	7	2	Increased battery consumption	1	1
Does not need fine control	5	2	Damages clothes	1	1
Easy to service	2	1			
Reliable	4	1			
Efficient	3	1			
Good/clever idea	1	1			

The preponderance of disadvantages (mentioned by relatively small numbers of respondents) concerned the vulnerability of joystick controllers to operator error and the general difficulty of imprecise, unpredictable movement. The second area of criticism is the positioning of the joystick controller. A small number of respondents felt they were not placed in the best position on the chair and that they can catch in clothing.

(e) Improved Public Attitudes

Answers to several questions indicated directly or indirectly that, largely due to the efforts of disabled people themselves, there has been a substantial shift of public attitude favouring disabled people. For example, 88% of the total sample agreed that the public attitude towards disabled people has improved over the past few years. Table H, below, indicates the predominate reason is to do with greater publicity for the problems of disabled people, and contact between disabled people and the general public. The second most frequently mentioned reason concerns recent work by disabled people to obtain greater degrees of independence and human rights. Interestingly, the 1970 Act was mentioned in this context by only 3% of the total sample.

TABLE H: REASONS FOR IMPROVED ATTITUDES TOWARDS THE DISABLED

BASE	533
	%
Publicity/public knowledge	33
People see/mix more	31
Public more aware	29
Growing tolerance/understanding	6
Accepted as human/not mentally sick	6
More buildings/facilities	8
Independence of disabled/fighting for rights	13
Mention of 1970 Act	3
Other	15

APPENDIX: REFERENCES AND ORGANISATIONS

A. Sources Used As Background Study

1. "Handicapped and Impaired in Great Britain". Amelia I. Harris et al. Office of Population Censuses and Surveys, HMSO 1971.

2. "Report on the Survey of Chronically Sick and Disabled Resident on the the Isle of Wight". Mrs. Brown, N. M. Thomas and A. Smith. Institute of Local Government Studies/Department of Social Administrators. University of Birmingham, 1972.

3. "Report on the Survey of Chronically Sick and Disabled People Resident in Newcastle-Upon-Tyne". B. Roycroft. Newcastle Department of Social Services. 1972.

4. "The Chronic Sick and Handicapped in Salford". T. Fryers, B. Banning and P. Newton, Department of Community Medicine, University of Manchester and Salford Department Of Social Services 1974.

5. "Report of the Working Party on Mobility Allowance". Central Council for the Disabled (now the Royal Association for Disability and Rehabilitation) 1976.

6. "Poverty and Low Incomes Amongst Disabled People". A submission to the Royal Commission on Distribution of Income and Wealth - Low Incomes Reference. The Disability Alliance. 1977.

7. "Wheelchairs and Their Users". A survey among users of National Health Service Wheelchairs in England and Wales, to establish their characteristics and attitudes to their wheelchairs and to the operation of the wheelchair service. D. Fenwick. Office of Population Censuses and Surveys for the Department of Health and Social Security. 1977.

8. "Whose Benefit?" An examination of the existing system of cash benfits and related provisions for handicapped adults and their families J. Simkins and V. Tickner. This study was undertaken by, and published by, the Economist Intelligence Unit Ltd. The Disablement Income Group was deeply involved in preparing the information.

B. Organisations Which Helped Mail Out Preliminary "Screener" Questionnaire

1. Arthritis and Rheumatism Council.
2. Association of Disabled Professionals.
3. Department of Health and Social Security, Blackpool.
4. Disabled motorist's Federation.
5. Disablement Income Group.
6. Disability Alliance.
7. Liverpool Association for the Disabled.
8. Multiple Schlerosis Action Group.
9. North Wales Community Action.
10. Royal Association for Disability and Rehabilitation.
11. South Lakeland Council for the Disabled.
12. Spastic Society.
13. Spinal Injuries Association.

Seminar 1

TRANSPORTATION
Chairman: *Group Captain R. E. Gardiner, DFC*

The Development of Technical Adaptations of the Motor-Car to the Requirements of Handicapped Persons
Mr. Zevering

Traffic Arrangements and Difficulties for the Handicapped
Mr. J. F. van Leer

GENERAL
Chairman: *Dr. E. P. Quibell, OBE, MRCS, LRCP, DCH*

The Young Person, Disability and Family Relationships
Mr. H. Wilke

Family Behaviours in Severe Disability—A Perspective for Family Development
Dr. Paul W. Power

LEGAL
Chairman: *Mr. G. Gilbert*

Legal Aspects of Rehabilitation Facilities Concerning the Family Development of Disabled People
B. van Buggenhout

A Parliamentarian Looks at Disability
Mr. L. Carter-Jones, MP

SERVICES
Chairman: *Mr. A. Kates, FRCS*

Identifying the Difficulties Created by Handicaps in the Family and Relating them to the Need for Care and Services
Dr. Margaret Agerholm, MA, BM, BCL(Oxon)

Financial Provision for Disabled Families
Mrs. Jean Simkins

THE DEVELOPMENT OF TECHNICAL ADAPTATIONS OF THE MOTOR-CAR TO THE REQUIREMENTS OF HANDICAPPED PERSONS.

Mr.Zevering

Mr.Chairman, Ladies and Gentlemen,
this lecture is entitled:
"The development of technical adaptations of the motor-car to the requirements of handicapped persons."

In the Rehabilitation Institute Muiderpoort at Amsterdam, extensive and complicated adaptations of motor-cars are advised and realised, side by side with the usual rehabilitation programme.

You will see on the slides that DAF cars were used. These are now replaced by Volvo 66 cars.

An important advantage of this type of motor-car is its automatic, a wide doorway with a door opening to its fullest extent and a seat high above street level, which facilitates getting in and out.

Frequent use is also made of the Simca 1000 automatic, which has the advantage that it offers more space and possibilities owing to the absence of a cardan tunnel.

If the left leg is missing or does not perform its normal function, while the right leg has enough power to operate the accelerator pedal, but not the brake pedal -even when the brake is applied- use may be made of a special brake but now controlled by hand. The brake is put into action by pushing the handle forward.

The special handbrake is mostly used in combination with forms of accelerating without the use of an accelerator pedal.

An example of this is the combination of a special handbrake with knee gas.

On the slide you can see the knee gas control unit, fitted at the left of the driver. Pressure of the upper leg will open the throttle.

If both legs do not function, the throttle will have to be made controllable by hand.

This can be effected by means of a throttle lever or a pivot, as on a motor bicycle.

Its construction is such that simultaneous accelerating and braking is not possible.

When the special handbrake is put into action, the engine is automatically throttled down.

Another form of hand throttle control is the segment gas.

You van see that the segment gas is on the right, immediately below the steering wheel and its form is the same as that of the wheel. Such a segment can also be fitted on the left.

When it is pressed in the direction of the steering wheel, the throttle is opened.

When the special handbrake is used, the driver forced to let the segment go.

When the right leg does not function, but the left one, however, functions satisfactorily, the accelerator pedal can be fitted at the left.

When new pedals are fitted or pedal functions are replaced by other means of control, the normal pedals are made collapsible to enable the garage staff to collect the car for repairs and to bring it back again.

This renders the car also serviceable for relatives, if required.

When the strength to stretch the arm is inadequate to push the special handbrake forward, use can be made of a segment brake. This is a control similar to that shown with respect to the segment gas. This is always a powered brake.

Also a very poor handpower could be a factor making it impossible to operate such a brake.

Our technicians have designed a brake equipment for which pressing power is no longer required. They arrived at an idea in which the dosage is a function of the lenght of pressing when using a constant, very slight pressing power. Consequently, pressing half the distance results in half the braking force, total pressing makes an emergency stop possible.

In this manner, it is in principle possible to bring a heavy vehicle to a standstill with the pressure of a little finger.

This brake is used in combination with segment gas.

To prevent both devices being simultaneously drawn in, both of them are fitted at one side under each other, under the steering wheel.

When the functions of arm and hand are, in addition, inadequate to turn the wheel when the car is not moving, a control booster should also be built in.

When the hand power is inadequate to operate the parking brake a special parking brake can be fitted. The lower thin handle can be moved upwards with only very slight hand force to loosen the handbrake and the thicker upper handle to tighten the brake.

When a patient's getting in and out is impeded because he or she cannot pass his/her feet through the opened door, a chair on a slide is indicated.

When getting in and out, and also during a drive, the chair can be moved by only a slight hand power into a position, giving sufficient space for the legs.

On the slide you also see two hand splints, one with a ball knob on the steering wheel and one on the throttle lever of the handbrake. The hand power in both hands of the patient driving this car is so slight that neither the steering wheel nor the throttle could be controlled in any other manner.

It is clear that the provisions made to motorcars can also constitute an adequate solution to problems that may arise in cases where the patient is conveyed as a fellow-passenger sitting beside the driver, as shown here with a chair on a slide on the right.

In this case, the left chair, too, was placed on a slide, because the provision was intended to be used by a transverse lesion patient who had to be able to slide from his wheel chair to the right seat and then to the driver's seat.

In the Netherlands, provisions in favour of handicapped passengers are frequently supplied, to improve living conditions. However, there are also patients who can perform work because they can be conveyed by a companion to and from their job.

Getting out of the car, for instance, for a patient having an artificial limb, is often impeded, because it is difficult to balance. A cross slide may bring relief in such cases. In the In the outer position the patient can balance himself by grasping the opened door.

In the inner position, the seat is adjustable both backwards and forwards.

The patient cannot be too tall, because otherwise he cannot pass the door opening in a crose position.

Another solution is a revolving frame. In this case the slide with the seat swings outwards around an axis behind the jamb in the middle, thus more space becomes available.

A frequently supplied provision is the special wheel chair to go into the car. The idea for the construction of this was originated in a technical working group and was realised by technicians in our workshop.

This provision is intended to be used by seriously handicapped persons who cannot stand and must be transported in a wheel chair, even in a motor-car.

A revolving frame is unbolted and turned outwards, then the wheel chair is pushed backwards over this frame. There upon the chair is lifted by means of an electrically operated screw spindle, after which the set of wheels is removed in two parts. Then the chair is lowered. Finally, the patient is turned inwards and the chair is bolted.

In case of contractures, for example with a patient suffering from bamboo spine or if there is a question of serious stretch spasm with a transverse lesion patient, so that he cannot adequately reach the steering wheel, an extension of the steering column is required. In such cases, other devices for control must often brought within the driver's reach.

When the function of the neck is limited, so that turning round is impeded, a broader mirror may be useful. The mirror consits of some mirrors placed in a holder, at an angle side by side and overlapping each other, and provides an angle of visibility of nearly 180 degrees.

An extended selector handle may render it possible to achieve a good control in case of impaired arm strenght.

This is also the usual method to bring the selector handle within easy reach of the patient in cases as, for example, hip contractures.

When the crank to open or close the door window cannot be turned because of contractures or insufficient power, the construction of a socket spanner ratchet on the handle shaft may solve the problem.

Moreover, you see on the dia behind the ratchet an extended door opener, because in this case, too, a normal opener could not be handled.

Still easier is, of course, an electrically operated window opener, of which ready made sets are on the market. This electric opener has, in addition, the advantage that its control can be installed in the most suitable position.

We are occasionally consulted by firms employing travelling salesmen, about the prevention or treatment of lower backache of some of their employees.

In the absence of obvious physical defects a well-moulded chair, adjustable in several ways may solve the problem.

Such chairs have a more stable seat and a better back support.

There are models where the side seams of the back have been left open, so that the chair can be easily adapted to some extent, also to individual requirements, for example by means of foam plastic.

Many of the important adjustments already shown have been brought together in our instruction car.

According to the handicap, the operation of a specific control can be executed in various ways.

As an example os this, you can see the carburettor of our instruction car. It has eight control cables instead of the normal single one. There are two cables for the foot-operated accelerator right and left, and one cable for the foot-operated accelerator of the driving instructor.

There are two knee-operated accelerator cables right and left, two segment-operated accelerators right and left, and finnaly a cable for the operation of the throttle-lever of the handbrake.

There are also many devices for the operation of the indicators, claxon, lights, window wipers and window sprayers.

In addition to instruction purposes, this car [illegible] used to estimate, in doubtful cases, what a patient [illegible] cannot do.

At present, there are eight such cars, spread over the same number of towns in the Netherlands.

Now I should like to show you some special adaptations of motor-cars.

Here you see the adaptation of a car for a dwarf who, in addition, is a wheel chair patient, but who is sufficiently independent to get in and out of the car.

A good view is provided by a well-adjusted seat in a chair on a slide.

All controls have been made within reach of the patient's hands as well as of his feet. Moreover, the right-hand chair, too, is fitted on a slide, because the folded wheel chair is drawn by the patient into the car, behind the right-hand chair. This chair must therefore be set far to the front.

This female dwarf, too, is sitting in a wheel chair, but she is not sufficiently independent to hop over from the wheel chair to the right-hand car-seat and then to slide towards the left-hand seat.

Following the same procedure as practised with the wheel chair for use in the car, she herself pushes her wheel chair backwards over the revolving lever-frame. When the chair is just above the frame, she can use a switch mounted on a rod, to operate the lift system.

The motor of the lift system stops automatically when the correct height of the revolving frame is reached.

Then she swings herself inwards, where the wheel chair is automatically locked in the car.

Finally, you see her sitting here, ready to start driving.

Here you see the adjustments to the car, which were required to enable a man, suffering from bamboo spine, as a result of Bechterew's Disease to drive his car independently.

First of all you see the sitting attitude of the patient, at first sight rather difficult. However, this adjustment of the seat provides a comfortable and stable seat for him.

Both the steering wheel and the other controls are brought within his reach by means of the extension of the steering-column already as shown earlier.

This is a survey of the adaptations that were required to ensure an easy operation of the handbrake and the selector handle.

Finally, the provision was completed by moving the window-opener to another place.

You will now see the car adaptations that were required for a patient suffering from a special form of juvenile rheumatism. The patient had serious contractures and such a loss of power that this was almost negligible.

An elaborate adaptation of the seat was necessary, with a reinforced lumbar support, collapsible lateral supports for, stability, and an adjustable head-support with adjustable headband to keep the head in its place during braking, because the strength of the neck was indequate for that purpose.

This shows a view of the driver's seat and the necessary controls.

Here follows a detailed view of them, including elbow acceleration, a well-moulded arm-support to absorb reactive pressures resulting from accelerating and braking.

Braking is made possible by means of the handle in the right hand by volar pressure in the pulse.

Moreover, all further controls are fitted on and in this handle, by means of switches operated with pressure of 20 grams, because the patient was unable to exert more strength.

Mr.Chairman, Ladies and Gentlemen,

With this lecture I hope I have made a contribution to the succes of this conference, and that I have made clear to you that there are many possibilities and solutions for disabled drivers.

I thank you for your attention.

TRAFFIC ARRANGEMENTS AND DIFFICULTIES FOR THE HANDICAPPED

Jan F. van Leer

1. INTRODUCTION

1.1. The national co-operative organisation

This introduction is made from out the Netherlands Society for Rehabilitation (NVR), the national umbrella organisation in the field of rehabilitation and care for the physically handicapped.
It is the "platform" on which 150 member organisations of physically and sensory handicapped, volunteers, professionals and various bodies, together with supporting funds meet each other.
The Society has many tasks, including: studying, initiating, stimulating, co-ordinating, evaluating and advising.
The field of operation is extensive: health care, education and training, purposeful work or - as an alternative - purposeful activity, increase of social security and furtherance of the integration of the handicapped. More will be said about this integration shortly.
The NVR co-operates with a large number of organisations. It acts, in many cases, as a discussion partner for the various ministries and semi-public services such as the GPO and The National Railway.
Then, too, there are good relationships with many private organisations with which the NVR comes into contact in different work situations. A close co-operation has developed with the ANWB (UK:AA + RAC) as regards informing the handicapped at touristic and recreational levels. The "Dutch Safe Traffic Society" provides special information for the handicapped. At provincial level, the Provincial Rehabilitation Foundations carry out the national policy, being stimulated by this and co-ordinating with it. From out these foundations the NVR is fed with specific information, evaluation etc.
In short, the NVR is a small organisation with a large number of contacts.

1.2. Integration

In order to reach efficient integration the handicapped needs to be given the possibility to follow the normal life pattern as well as possible. The greatly improved medical techniques and the development of modern apparatus in the field of means of transport enable him to a great extent to achieve this if society only takes his specific problems into account. These problems occur at different levels and in different areas, depending on the diversity of the nature and seriousness of the various handicaps. More will be said about this later. The handicapped really wants to be independent or at least to be involved in social life with as limited help as is possible.
A chain of provisions, which must be built up in a balanced manner, is necessary for entire integration of the handicapped.
Should one of the links be missing from this chain, serious disturbances in the possibilities of integration occur.

Consultant of the Netherlands Society for Rehabilitation

The chain is formed mainly by:

- adapted housing and living conditions for the handicapped, the eventual necessary assistance entailed;
- the reachability of, access to and use of buildings and provisions for the handicapped;
- the availability of transport that can be used efficiently, not only private transport (car, motorized wheelchair, electric wheelchair, etc.), but public transport too (train, tram, bus, taxi); special transport for those unable to use public transport and not possessing their own means of transport;
- adapted transport facilities, so that the handicapped can move from place to place without insurmountable restrictions;
- means of communication (telephone, alarm signals, etc.);
- financial means permitting the acquisition of available provisions.

2. NUMBER OF HANDICAPPED

Until recently uncertainty reigned with all the authorities as to the policy to be adopted. because the number of handicapped was unknown. In the recent CBS (Central Bureau for Statistics) report "The physically handicapped" a detailed insight is given as to the number of persons with one or more functional disturbances. Subdivisions are made as to type and seriousness of these disturbances.

In total there are 8.7% or more than one million Netherlanders physically handicapped by one or more functional disturbances. About three out of 1,000 inhabitants or about 40,000 Netherlanders are, according to this examination, dependent on rolling transport for their movement from place to place outside the home, because they are unable to walk; either with the help of a third person and/or aids.

In an average Netherlands town of 100,000 inhabitants there are, on the basis of the afore-mentioned examination about:

3,900 persons with disturbances in staying power
3,700 persons with disturbances in walking
1,400 persons with impaired hearing
820 persons with impaired sight.

In this town, on the basis of functional disturbances:

2,500 persons have problems when visiting public buildings
3,100 persons have problems when using public transport
1,400 persons cannot even use public transport at all.

Another interesting figure is, that in 1977 more than 90,000 Netherlanders received exemption from car taxation because of their handicaps. This is only granted when a serious restriction in mobility is concerned, and a car is used, completely or almost completely for transport of the handicapped. The recorded increase in the use of roads etc. by the handicapped is accounted for by:

- the progress of medical knowledge resulting in more handicapped remaining alive and after rehabilitation being able to function again (to include road accident victims);
- the progress of the technique, resulting in still better aids and well adapted vehicles;
- improvement in public transport (e.g. the Railways);
- the high standard of living in the Netherlands, making the acquisition of special aids and adapted vehicles possible;

- the improvement in the field of general accessibility into society, stimulating one to go farther afield.

Not only does the handicapped profit from the improvement in transport provisions, but more of this later.
In general the entire community benefits from it. Parents with perambulators have similar problems, but these are mostly less serious.

3. MEANS OF TRANSPORT

Many handicapped have to depend on the use of walking-aids such as crutches or sticks and on rolling transport, according to the seriousness and type of function disturbance(s). There are many kinds of special means of transport for the handicapped. The most important are:

- manually operated wheelchairs
- pushcarts
- hand propelled vehicles
- electric wheelchairs for indoors and outdoors
- motorcars with limited speed, with either electric or petrol engines
- adapted cars
- specially adapted buses (there is a great shortage of these).

It is evident that there is an increasing mobility of the handicapped to be noted. Traffic conditions must be adapted to this need.

4. NEW PARKING REGULATIONS

On 1 July 1977 new traffic regulations came into force. On that day the place on the road for the invalid vehicles was regulated. Now the handicapped in his invalid carriage has a choice from footpath, cyclepath and road. On 1 September 1977 the municipal regulations were supplemented with the national invalid's parking badge and the invalid's parking disc. The new parking regulations are especially designed for those who have an invalid's parking badge, which entails:

- exemption from prohibited parking for maximum 2 hours. The time is indicated on the "invalid parking disc".
  A black arrow indicates the time of arrival.
  Exemption does not apply to prohibited parking indicated by a yellow line on the curb.
- parking exemption is valid for the whole country. Municipal licences remain valid locally.
- the special parking badge can also be issued to non-handicapped for transporting handicapped passengers.
- the badge may not be used if there is a parking space in the immediate neighbourhood.
- the car can be parked for an unlimited time in parking zones.

Moreover, a new sign, 54c, "General Invalid parking space" has been introduced.

5. TRAFFIC PROVISIONS (particularly for motory handicapped)

It is actually amazing that so little research on necessary traffic provisions for handicapped has been carried out in the Netherlands. Four years ago a detailed article about these traffic provisions was written. Recently two reports on research, in Arnhem and Bergen op Zoom, have been presented. A route network between home and destination of the handicapped was set up. These are important stimulants for the policy to be adopted.

Data on traffic provisions, but also on the adaptation of buildings, housing and recreation facilities are to be found in the loose leaf publication "Geboden Toegang", which was published by the Netherlands Society for Rehabilitation (NVR) in co-operation with the "Adaptations for the Handicapped Foundation" (AVG).

Also included in it are the criteria for the international accessibility symbol that is awarded by our umbrella society to buildings and provisions that can be reached, are accessible to and useable by the handicapped without special help being given to them.

There are at present about 1,500 buildings in the Netherlands that have been given this symbol after being checked by a member of the body of voluntary advisers, mostly handicapped themselves.

The new compulsory stipulations of the National Model Building Regulations (11th, 12th and 13th amendments), issued at the end of 1975, will certainly lead to extensive improvements in the accessibility of new buildings. This furtherance of integration should be similarly applied to all aspects of traffic.

5.1. Parking spaces

It is desirable that sufficient reserved parking spaces should be set aside for handicapped motorists, both drivers and passengers. This should be done near all important buildings, such as shopping centres, post offices, stations and stadiums; but also in general parking areas and particularly in parking garages. Consider your municipality in this respect. Are the handicapped catered for and are the facilities in the parking garages you visit really effective? When reserving parking spaces these should be chosen so that there is a completely free pavement of 8 to 10 cm height on one side.

This facilitates getting in and out of the car for a number of handicapped. There is an added advantage if the handicapped himself has to pull his wheelchair inside behind the front-seat.

Near the parking spaces there should always be a lowered curb or small ramp. These special spaces should be at least 330 cm. wide, preferably 350 cm. or more.

This also applies to the angled parking spaces at the side of the road. Parking spaces parallel to the pavement should be, if possible, 100 to 150 cm. longer than normal for the handicapped, because quick and resolute manoeuvring is difficult for some handicapped.

Reserved parking spaces for the handicapped should be spread as near as possible to shopping centres, etc. so that the walking distances are limited as much as possible.

5.2. Differences in height

Differences in height should be avoided as much as possible for non-motorised handicapped. Thresholds up to 2 cm. are acceptable. When the differences are greater, ramps with a gradual slope should be introduced, or lifts or platform lifts installed.

Acceptable gradients are :
difference in height up to 10 cm. = maximum gradient 1 : 6
difference in height up to 35 cm. = maximum gradient 1 : 8
difference in height up to 75 cm. = maximum gradient 1 : 12

A ramp should preferably be given a gentle slope, e.g. 1 : 20. There should be a horizontal resting place every 9 meters. A handicapped person in a wheelchair must exert a great deal of energy to ascend ramps. The ramps should have handrails, depending on the gradient. Next to the ramp, unless the gradient is gentler than about 1 : 20, should be steps, because handicapped with leg prothesis often have more difficulty with a ramp than with steps.

The correct measurements for steps are :

riser : recommended minimum 8 cm., maximum 14 cm.

tread : recommended 32 cm.

The form of the step - nosing is important as the foot must not be caught in it. Open steps should not be used as these can be dangerous.

Differences in height greater than 150 cm. should preferably be bridged by lifts. The minimum measurement for lifts and platform lifts is 110 x 140 cm.

5.3. Pavements

Pavements may in the Netherlands be used by the handicapped in vehicles provided the speed is adjusted to that of the pedestrian. As well as being wide enough (minimum about 150 cm. though preferably 180 cm.), they must have no thresholds higher than 2 cm. and should lie sideways almost horizontally. This can give many problems in pedestrian territories in connection with drainage. Inclination 1 : 100, height of pavement 8 cm. preferably not more than 10 cm. Pavements should have a flat and hard surface.

Sufficient approaches to the pavements should be made : near all important buildings, housing and shop complexes and at every street corner. These approaches can be constructed preferably by lowering the curb to 2 cm. above road level, or by using specially prefabricated bevelled curb stones (short ramps).

Special care must be taken to avoid parked cars blocking the entry (a non-parking sign is advisable prohibiting parking for a length of 200 cm. on the road).

Keeping strictly to the measurements, grading 1 : 6, maximum height 10 cm., is important, otherwise there is a danger of "dumping". Where the pavement is overall higher than 10 cm., it should be lowered to this height at this point. In some municipalities the problem of making sufficient approaches to the pavement is being tackled efficiently and systematically. This example should be followed by all municipalities.

5.4. Pedestrian crossings

Pedestrian crossings should be approached from lowered or ramped parts of the pavement. If the roads are wide and there are traffic islands these should be passable, the passage being at least 150 cm. wide. A chain barrier at the pedestrian crossings can better be replaced by a firm barred barrier so that this can be held on to.

5.5. Handrails

Handrails that are easy to grasp, placed near a long approach to an entry are a boon to those with walking difficulties, restricted staying power or balance disturbance.

We come across far too many of these difficult to grasp handrails. Even worse is the absence of handrails.

5.6. Traffic lights

The timing of traffic and pedestrian lights for a safe crossing for handicapped and the aged should be suitably adapted. 75 cm. a second after the beginning of the green light phase is a desirable crossing speed. The handicapped and aged should be advised always to wait for a new green phase.

5.7. Push buttons

The push buttons at traffic lights and in lifts should be accessible to a wheelchair user, and should preferably be about 100 cm. high.

5.8. Passage ways

Passage ways between barriers, near gateways, etc. should provide a free passage of at least 100 cm. enabling the handicapped to proceed unhindered in the vehicles they usually use.
There is a small number of wider vehicles for handicapped that need a free passage of 160 cm. These should be taken into consideration e.g. for parking.

5.9. Traffic barriers

Seriously handicapped sometimes complain that they experience such heavy jolts from these traffic barriers, in the form of irregularities in the road surface as used in residential areas for the reduction of speed. These barriers seriously hinder their mobility. Drains protected by gratings or drains that are sunk too deeply can also give problems. Special attention should be paid to the additional decorations of premises so that the decorative paving, plant tubs, trees, etc. too do not present obstacles to the handicapped. These should be kept as far away as possible from the pedestrian route.

5.10. Gratings and grooves

The size of mesh in the gratings should not exceed 2 x 2 cm in the interest of those dependent on crutches or sticks. Special grooved tiles for bicycle stands can also prove obstacles on pedestrian routes.

5.11. Wheelchair routes

There should be special "wheelchair routes" between the parking spaces and shopping centres, stations, stadiums and other frequently visited buildings in towns. These routes should systematically have lowered pavements and pavement approaches (ramps) and a passage through the traffic islands. (These special "wheelchair routes" should be regarded as an intermediate phase until the entire municipality is equipped with adapted pavements and passable traffic islands). Attention should be paid to all the "links" in the route-chain.

5.12 Cycle paths

As far as the handicapped are concerned who use cycle paths or the roadway, particularly on mopeds or special vehicles with engines of a smaller capacity than 50 c.c. or electrically driven, it is not necessary, in general, to provide facilities. Cycle paths only need to be wide enough to enable a vehicle used by the handicapped to pass (in general a maximum width of 100 cm.). They should be as level as possible.

6. SANITARY PROVISIONS

The lack of adequately adapted public toilet facilities means exclusion for the wheelchair users. The local councils should cater for this particular provision, seeing that it is available at one or more places. A systematic net of adapted provisions is being built up along the motorways. At the moment, because of the new regulations laid down by the Ministry of Transport in 1973 for facilities along motorways, 58 filling stations have an adapted toilet and there are 7 fully adapted restaurants along motorways.

7. PUBLIC TRANSPORT

Many handicapped with difficulty in walking are helped when the difference between the tram and bus stops and the height of the floor of these vehicles is as small as possible. It is therefore desirable that:

- the bus should be entered from the pavement and not from the road,
- raised platforms should be used at tram stops. This also increases the total speed of getting in and off the tram. These platforms should be approached by means of a ramp and, if necessary, have steps and handrails or fencing. In The Hague great benefit is derived from these provisions.

It should be generally known that many handicapped cannot stand for a long time. At public transport stops, but also in shopping centres, there should be seating accommodation. Most of the shelters in the Netherlands leave much to be desired in this respect. Very often there is no means of support, but instead a post that digs into one's back. An appropriate application of "ergonomics" in the whole question of transport would bring about many improvements.

The Dutch National Railways have introduced a large number of measures during the last few years to improve transport of the handicapped. An information sheet on this subject, obtainable at each station, is published annually. Good traffic facilities at stations, especially parking spaces, an adapted call box, seats in shelters at tram and bus stops are a must for the handicapped.

8. SENSORY HANDICAPPED

What has been dealt with so far applies particularly to the motory handicapped. Now what follows is of special importance for the sensory handicapped.

8.1. Visual handicapped

Consideration should be paid to the blind and the partially sighted in the following ways:

- Removal of all obstacles that hang lower than 200 cm. on the walking route. The sighted person can avoid these, but they form a great danger to the blind or partially sighted.
  Important obstacles are: lamp posts, traffic signs, parking meters, plant tubs, etc. The posts of the first two provisions should preferably hang above the pavement so that the "traveller" does not bump against them en route. The signs should be attached, as far as possible, to the essential posts. An obstacle-free route of at least 150 cm should be reserved.
- Addition of ground indications that can be clearly felt with the blindman's stick near hanging objects such as boards bearing public transport timetables.
- Addition of contrasting colours is necessary at places that can be a source of danger to the partially sighted. This has been done on all the stairways of the Dutch railway stations.
- Addition of different types of material, distinguishable to the blind, near the approach to stairs, pedestrian crossings, etc. This can be achieved by two or more rows of rubber tiles.
- Installation of acoustic or vibrating signals near pedestrian crossings that are important for the blind, such as near institutes and workshops for the blind, homes for the aged and concert halls. In some Dutch towns there are good examples of the realization of these provisions.

- Installation of warning signs, easily heard, at danger spots, for example where tram rails cross pedestrian routes.
- The transition from pavement to road at lowered pavements, exits and at passages through traffic islands should be easily felt with the stick. The difference should be about 2 cm.
- Addition of about 50 cm. horizontal hand rail at stairs, provided it does not protrude into free space.
- Attention should be paid to sign posts, street names, press buttons, etc., that the letters are easily distinguisable, and that lighting is adequate. The partially sighted will greatly benefit by good positioning and letters that are as clear as possible.
- Necessity of easily felt figures and letters, for example lift buttons, name plates and room numbers, etc. in relief, the figures being about 3 cm. high. The partially sighted profit by lift buttons, numbers and sign posts that are lighted from behind.
- Special lighting is desirable at pedestrian crossings. This is most important for persons with decreased sight. Perhaps a contrasting light colour would be advantageous for them. This should be further examined.

8.2. Auditive handicapped

In general it is not necessary to make special provisions on the roads for the group formed by the deaf and the partly deaf. For them it is important that there should be on all sides clearly visible light signals at dangerous points, where the auditive are warned by sirens and bell signals. This is specially applicable to exits for firebrigades, etc. and also at points where trams or trains cross the pedestrian and car routes.

9. COMMUNICATION PROVISIONS

The handicapped are usually quite dependent on the use of communication means. Because of this, it is most important that public telephones should be made as usable as possible for the handicapped. This applies to call boxes near stations, in shopping centres, near important buildings, near road restaurants, etc. The handicapped should be able to give a message so that they can be fetched from a certain point. The Netherlands has not made much progress in this respect. An "open box" with a top, a lowered telephone as well as a hinged seat are not very expensive provisions. These telephone facilities should, however, be protected from adverse weather conditions.

A sign for breakdown is being developed for the handicapped. A decision regarding its use in the Netherlands is expected shortly. At an international level we have urged a similar sign to be developed through Rehabilitation International.

In Sweden special exchanges, in which handicapped work, function by means of radio communication, enabling the seriously handicapped motorist to keep in contact. This increases his safety considerably. Unfortunately we have not got so far yet in the Netherlands. We are under the impression that such a system should become available to Dutch handicapped, too.

10. UNIFICATION OF DIRECTIONS

To refer the handicapped to traffic provisions, a number of traffic signs and sign posts should be designed and put into use.

Some of the points that should be taken into consideration are:

- where are the special parking spaces?

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- where are the wheelchair routes?
- where are the lifts to be found?
- where is there an adapted entrance?
- on which floor are the special parking spaces for handicapped in a parking garage?

For this method of indicating the way the international symbol for accessibility can be used, if desired in combination with other symbols or texts.

The benefit of "accessibility guides" that can provide information about adapted facilities, is great.

11. NEW DEVELOPMENTS

It is desirable that, when experiments are being made and new types of projects are set up, the interests of the handicapped should be taken into consideration from the outset. Naturally conflicting interests should be weighed against these. One cannot demand that pleasing flower boxes or plant tubs that brighten up the surroundings, should not be placed where pedestrians pass, because the partially sighted or blind would experience difficulties.

Town planning should certainly consider the disadvantages of a main road being planned to cut through certain areas, thus depriving many handicapped of possibilities of integration.

Recommendations are being made for research to begin, not only nationally but also internationally, each with their special norms. The following points are some of the items that should be studied:

- what is the crossing over speed that can be attained by the various groups?
- how can the materials for crossing be unified at important crossings?

  A national work group could advise on the choice of a definite system of tangible road surface materials for the visually handicapped.

  Pedestrian routes could be made with these for this category of handicapped. In Japan such routes are equipped with yellow studs.
- further development of uniform perceptible sound signals for the blind at crossings. Many experiments are being carried out. Crossings that lie close together, for example near intersections of roads, present many problems. On some installations the buzzers always work, on others only during certain periods and yet by others only after a special push button has been pressed. Very often the visually handicapped has great trouble in finding this button.

  In Japan and Sweden "vibration posts" with directions in braille, producing a sign that indicates when to cross, are being used. Perhaps the further development of instruments that the handicapped can carry with him, and which give him a signal, is possible. The advantage would be that the other road users would experience no trouble. A committee of the Dutch Society of the Blind is engaged on a study of these problems. It must be stressed that there is a serious lack of co-ordination in the execution of this research.

  In several places in the Netherlands different types of facilities are being installed. The longer the government puts off issuing clear instructions, the more difficult it is to reach unification.

  It is of the greatest importance that the developments in various countries, especially in Japan and Sweden, should be studied further.

12. EDUCATION

Becoming acquainted with good provisions should be part of the nation's education. How often do we find expensive adaptations or aids out of action because of misuse, or worse still, because of destruction? This is a real problem that needs tackling. The numerous broken lifts in stations, parking spaces reserved for the handicapped being used by others, ramps near buildings being used by moped riders, are but a few examples of problems caused by the non-handicapped, thus hindering integration.

13. CONCLUSION

The above summary is probably enough to make it evident what an important task the study and solution - as far as possible - of traffic problems for the handicapped is. Plans should be developed and the means to execute them reserved.
The handicapped realize quite well this cannot happen all at once. But that something must be done, and that an enormous step forward can be taken in a few years in a town or district, is certain. It should not be too great a problem when the desirabilities in broad outline are known:

- to have the necessary adaptations made at once when town extensions are carried out,
- to have improvements made when roads are being repaired,
- to start drawing up a circulation plan for the handicapped in the districts where this is most needed, and then to realize the necessary adaptations.

Those who doubt the utility of these provisions are advised to sit in a wheelchair for one day, or to be blindfolded, and then to take part in the traffic. Very quickly will they be convinced of the necessity!

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FAMILY BEHAVIORS IN SEVERE DISABILITY: A PERSPECTIVE FOR FAMILY DEVELOPMENT

Paul W. Power*

Family influences have a direct bearing on the attitudes and behaviors of disabled persons and these influences are uniquely related to rehabilitation outcome. Two significant influences have been identified in the author's research with families, and these behaviors provide both a perspective and a resource for helping the patient towards productive goals and the family to adapt to illness or disability trauma. Such a helping model has been devised and its implementation has enabled the patient and family members to achieve renewed satisfactions in life.

INTRODUCTION

Chronic illness or disability not only affects one person. An individual's disabling condition will have an influence on all persons with whom he has a close emotional involvement or frequent social interaction. In turn, the manner in which a family responds to illness in its midst can have a marked effect on the course of that illness (Rakel,R.; Principles of Family Medicine, W.B.Saunders Co., p.342,1977). The family is the most central and potent external force not only in shaping the individual personality but also in the expression of physical illness (Jaffe,D.;"The Role of Family Therapy in Treating Physical Illness," Hosp.&Commun. Psy., 29,p. 169, 1978).

Studies have suggested that family influences have a direct bearing on the attitudes and behaviors of disabled persons and indicate that these influences may be importantly related to the outcome of rehabilitation. Varied authors have recognized that successful rehabilitation cannot occur without family participation and have cited the need to bring the family into critical phases of the process (Lindenberg,R.; "Work with Families in Rehabilitation," Rehab. Coun. Bull.,p. 67,Sept., 1977; Barsky,A.; "Patient Heal Thyself: Activating the Ambulatory Medical Patient," J. Chron. Dis.,29,p.586,1976; Bruhn,J.; "Effect of Chronic Illness on the Family," J.Fam.Proc.,4,pgs.1057-1060,1977). Yet no clear pathway has been found between specific family influences and the rehabilitation of the family member. More attention needs to be paid to identifying these intervening variables related to rehabilitation goals.

This report focuses on one research study that has explored and identified family influences or behaviors on the rehabilitation of many neurological patients. It also describes the patient and family reaction to the disability, the determinants of these reactions, and importantly, in the perspective of family behaviors, explains a family helping model that can be utilized by both family members and health professionals to facilitate the life satisfaction of the patient.

METHODS

As a rehabilitation psychologist employed in a neurology outpatient clinic, the author has had the added opportunity since 1975 to work with

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15 Huntington's Disease, 30 Multiple Sclerosis, and 5 Parkinson's Disease patients and their families. The ages of the patients and their spouses range from 30-53, with a family income between $12,000-$16,000. Ten of the Huntington's, 17 of the Multiple Sclerosis, and 3 of the Parkinson's patients are men. Though the diseases had been diagnosed many years previous to the author's introduction to the patients, he had been asked to intervene only when the deteriorating effects of the illnesses had finally made a strong physical and emotional impact on the patient. For the patients it was the first serious exacerbation of their disease, and for the first time the patients considered themselves severely handicapped to meet most of their everyday life demands.

The patients were initially seen at the author's office for two sessions. During this time the patients' emotional reaction to the disability was assessed and rehabilitation goals were explored. They were told that their family would be utilized in their own adjustment to the illness, and consent was obtained. The family members were seen at the author's office for two sessions, once every three weeks, at which time their emotional reaction to the illness was determined. The patient and the family were then seen together in their home once a month, during which further problems were identified and the author began to help the family adapt to the disability trauma. The observational method (Fox,D.; The Research Process in Education. New York, Holt, Rinehart & Winston, 1969), with a particular focus on the attitudes and behaviors of family members, was employed. It provided the author with a way to view human behavior in a natural setting. A Q-Sort method for gathering information was also used during the family visits, for it provided the opportunity for the more reticent family members to express their own attitudes concerning the illness of the family member.

PATIENT REACTION TO DISABILITY

In a chronic, degenerative illness individuals must cope daily with their own interpersonal needs, family dynamics, and the biologic concomitants of the disease. The author discovered, however, after initial meetings with the patients that the majority of the men with the neurologic illness had adjusted poorly, in contrast to the women who generally were adapting well to their condition. With few exceptions the men, realizing they were unable to return to full-time employment, withdrew from most of their social and family activities. Though physically capable of performing many household, leisure time pursuits and even working part-time at their previous jobs, they became rocking chair men, mainly inactive during the day and showing an unwarranted dependency upon others. They were depressed, distant, and expressed a fear of being abandoned. The men seemed adrift between the world of the sick and the world of the well. Yet it was the author's observation that the illness appeared to be a way for the men to compel attention. While unhappy that they no longer were the principal breadwinner for the family, the men were able in their dependency to exert control over their family. But those few men, moreover, who did continue to be active, as much as their physical condition permitted, verbalized the conviction that the illness was only a handicap. They revealed that they were aware of their capabilities, and the author observed that they seemed to possess a strong determination to be as active as possible, and this was reinforced by the responsive behavior of their family.

Most of the women with the neurological illness, however, continued in their family roles. Though women are less inclined to adopt the sick role when they have pre-school children in the home, this inclination was maintained when the children were older or had left home. Though they stated that they were occasionally depressed over their weakening physical condition, they believed that other family members needed them. Family members conveyed the expectation that the ill person was to continue to perform the family duties for as long as possible. But some of the women became emotionally overwhelmed at their deteriorating disease. They were constantly irritable, unsociable, and neglected performing many of their household duties. Interestingly, a family history revealed that these women had worked at another job apart from the home, and they harbored much resentment at not being able to return to it.

FAMILY REACTION TO DISABILITY

In a chronic illness or disability situation family members are constantly forced to be involved in re-organization and re-adjustment of their daily lives. With all of the families there was a temporary crisis in accomodation to new functions and responsibilities with the severe exacerbation of the illness. Of the fifty families sixteen were able to make the changes adaptively; the other families, unfortunately, displayed mal-adjusted behaviors.

Adjusted Families. Though all the family members felt a sense of personal loss, when necessary family responsibilities were able to be re-distributed among family members. There was a willingness on the part of the family to function or to change according to the changing needs of the environment. Also, family members openly discussed the importance of compromising or consolidating some family goals, i.e., vacation plans and college education for the children. In attending to the physical needs of the patient, a few families believed they were growing closer together. Various coping mechanisms were employed to deal with the uncertain progression of the disease, such as altruism, denial, sublimation, and an increased rate of activity among the family members that was not detrimental to family life. Surprisingly, many families became more religious, turning to charismatic groups in Christianity for hope and a possible cure. When a cure was not forthcoming, religion was then utilized as a source of strength. Altruism was shown, moreover, by participation in self-help groups associated with the particular disease, and sublimation was manifested through expressing the family's frustrations or disappointments by their combined social past-times, hobbies, or planning for the future. Denial was focused on not believing in the long-term implications of disease progression. Generally, the family members re-oriented their lives to encompass the new and serious illness related events, and there was a sense of normalcy and control in everyday family affairs.

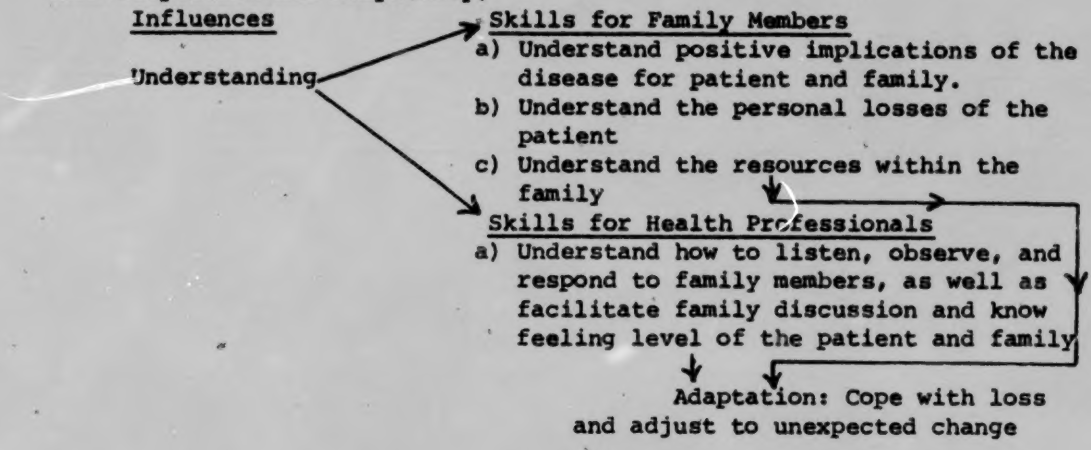
Mal-adjusted Families. For most of the families the illness represented a source of trouble. With progressive deterioration the family experienced prolonged stress. Irritability, resentment, frequent arguments, and the placing of inappropriate demands on the health care provider dominated the family scene. In a few families the chronic illness created new or revised former disruptive behaviors, i.e., excessive drinking or marital infidelity. The children showed many hypochondrical symptoms or stayed away from home for prolonged periods of time. A conspiracy of silence formed around the discussion of disease-related information, facts that could have been useful for adjustmental purposes. The family members appeared to be continually angry over the presence of the illness, and felt that each was alone in coping with this disease intrusion.

DETERMINANTS OF PATIENT AND FAMILY REACTION

The causes that contributed to both the mal-adjusted and adjusted patients and families did not only reside in cultural backgrounds, financial resources, familiarity with previous stress, family communication patterns, pre-disease family pathology, the ability to use community resources, and early family related intervention by health care providers. The author discovered that there were other, more dominant reasons, and these reasons were conceptualized in two words: Understanding and Expectations. Understanding refers to a knowledge of the productive, residual assets of the patient, the emotional needs and personal losses of the patient, and the resources existing within the family, i.e., affection towards each other, sharing of responsibilities, open and honest communication. It was this lack of understanding that precipitated many negative, patient behaviors and stimulated family maladjustment. Expectations point to the attitudes that the family members had towards the capability of the patient. When such expectations were low, the patients showed more regressive behavior and the family displayed a poor adjustment to the disease. Consequently, upon gaining an awareness of the suggested causal relation between understanding and expectations and the adjustmental pattern of the family, the author then utilized these influences as the principal resources for a helping model to assist the families to adapt to the illness and to regain a level of productivity.

FAMILY HELPING MODEL

After determining the reaction of the family and patient to the disabling condition, the author then formulated a conceptual base for his family counseling and established goals for this intervention. The conceptual base included: 1) A family changes when its way of thinking changes (Ackerman,A.; Treating the Troubled Family, Basic Books, 1966); 2) The family is held together by mutually reinforcing patterns which include the attempt at meeting the varied needs of family members (Satir, V.; Conjoint Family Therapy, Science & Behavior Books, 1967); 3) Individuals can be assisted to change when helping professionals first assist family members to explore their problems, resources, needs, etc., and then begin to understand these same factors (Carkhuff,R.;The Art of Helping, Human Resource Development Press, 1977). The established goals for the intervention were two: 1) To help the family live adaptively with the disease and 2) To assist the family to achieve a sense of competency. To accomplish these goals, both the family members and concerned health professionals need specific skills. These skills can be developed within the framework of the family influences of understanding and expectations. The following diagram outlines the influences and skills that lead to this adaptation and competency:



Influences

Understanding

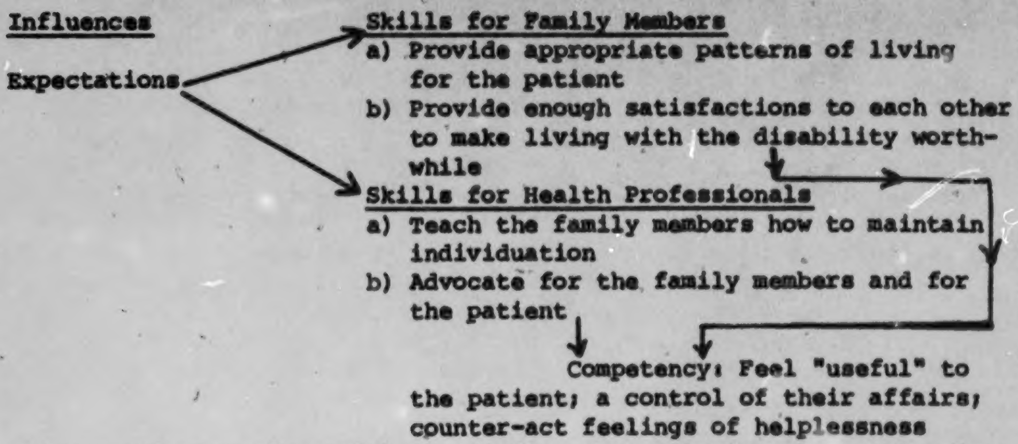
Skills for Family Members

a) Understand positive implications of the disease for patient and family.
b) Understand the personal losses of the patient
c) Understand the resources within the family

Skills for Health Professionals

a) Understand how to listen, observe, and respond to family members, as well as facilitate family discussion and know feeling level of the patient and family

Adaptation: Cope with loss and adjust to unexpected change



Influences

Expectations

Skills for Family Members

a) Provide appropriate patterns of living for the patient

b) Provide enough satisfactions to each other to make living with the disability worthwhile

Skills for Health Professionals

a) Teach the family members how to maintain individuation

b) Advocate for the family members and for the patient

Competency: Feel "useful" to the patient; a control of their affairs; counter-act feelings of helplessness

In counseling sessions with the family, the emphasis was on: a) Helping the family members to explore and understand their needs, perceptions, and resources, b) Helping the family members to ventilate their own feelings related to the disability, c) Showing the family members how the residual assets of the patient could be utilized to help the ill person feel more productive around the house, d) Encouraging the family members to discuss their expectations for each other and to review the illness event from their respective viewpoints, e) Teaching the family to listen to the needs of the patient and to be responsive to the ill person's emotional concerns. This flow of information and expression of feelings, consequently, did much to ease patient and family distress that was prompted by ambiguity and uncertainty. As the family members understood how the patient could still function around the house or in a previous occupation, they became more hopeful about living with the illness and then developed their own constructive coping styles. Also, the higher the expectations from the family, the more the patient was willing to participate in social activities and household duties. Generally, the implementation of the skills gave the family added feelings of usefulness and indicated the many satisfactions that still exist in the family despite the disability experience. The family developed to a new way of life.

CONCLUSION

The utilization of the family in severe disability places health behavior in a social context much broader than that circumscribed by the doctor's office or the hospital. Understanding family influences in severe disability, and then utilizing them in family counseling, highlights the importance of the inter-relationship of social, emotional, and pathological forces in the care of the disabled. Such influences also indicate that a partner in the patient's rehabilitation efforts is the family.

LEGAL ASPECTS OF REHABILITATION FACILITIES CONCERNING THE FAMILY DEVELOPMENT OF DISABLED PEOPLE.

Beatrice Van Buggenhout

ABSTRACT

The legal concern for the disabled has long been focused on medical, financial and professional difficulties. Psychological, social and family problems only recently led to legislative provisions. Collective facilities and individual measures have now been enacted to foster psychological aid. Sickness insurance and public health regulations developed home care and prevention. Educational facilities were ruled to acknowledge - as far as possible - parental responsibility and financial support was granted as a basis or help for a normal family life. However the organization and legislation concerning professional rehabilitation has sometimes neglected the impact of rehabilitation efforts on family life and the civil law status of the disabled doesn't always meet their specific needs. The basic human rights of the disabled must be legally protected and special efforts have to be undertaken by the authorities to foster social and cultural integration and avoid all forms of segregation and labeling.

INTRODUCTION

The aim of this paper is to analyse the recent trends in the legislation concerning the disabled, with regard to the family development of disabled people. The analysis will be mainly based on the Belgian legislation, jurisprudence and literature (cfr. B. Van Buggenhout. Het juridisch statuut van de minder-valide, 581 p., 1975, Story, Gent-Leuven), with some references to the situation and literature in other European countries. Critical remarks concerning this evolution may be useful guidelines for policy-makers and legislators who have to determine rehabilitation policy and have to enact the corresponding legislation.

BACKGROUND AND EVOLUTION OF THE LEGISLATION CONCERNING THE DISABLED

The general legal concern for the disabled is rather recent. Till the beginning of this century governments were only concerned with war invalids and had little attention for other disabled. As social security schemes developed the concern for the professional and economic consequences of disability was enhanced. It was stressed that the worker and his family needed protection against the risk of the loss of income caused by disability and that adequate medical aid had to be provided to restore his capacity to work.
Legal measures were enacted to grant medical care and basic financial support to the disabled workers. After the first world war these facilities were extended - in a limited measure - to other groups of physically handicapped.

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General programs concerning all disabled were only introduced after the second world war. Economic prosperity had enlarged the financial possibilities and social policy was aimed at the realization of the welfare state. The urgent problems of the disabled concerning medical, financial and professional aid retained the attention of law-makers in all European countries. Psychological, social and cultural aspects were neglected. Either they weren't acknowledged or they were looked upon as the exclusive competence of private persons and organisations, without any need of public intervention.

During this period legislation was principally aimed at granting individual benefits. Dependents at charge could be taken into account to determine the amount of the benefits. Also could the income of other members of the family be a reason for limiting or witholding benefits. But no further attention was paid to the family of the disabled.

RECENT TRENDS IN LEGAL PROVISIONS CONCERNING THE SOCIAL ASPECTS OF DISABILITY

During the past decade growing interest has been shown for the quality of life and the well-being of the people as opposed to plain financial wealth. As rehabilitation legislation is moving into that same direction, there is a growing awareness of the complexity of the problems related to disability. The need for a global approach is recognized, and the interaction of medical, economical, professional, social and psychological, aspects is acknowledged (C.D. Moulijn, K.E. Huizing-Büchli & M.W.J. Menken. Leven met een handicap. Mogelijkheden en beperkingen, 179 p., 1975, Samson, Alphen a/d Rijn). Rehabilitation efforts have in the past often been hampered by the lack of coordination between the different measures taken towards the same person.

It is also obvious that the efficieny of rehabilitation is limited when no attention is paid to the important psychological, social and cultural effects of disability (C.L. Tomas. Le handicapé physique. Son orientation. 378 p., 1973, P.U.B. Brussels). Especially the family situation of the disabled and the attitude of the family towards disability and rehabilitation are of the utmost importance.

To cope with the family problems with which disabled persons can be confronted a network of facilities has been created that promotes the possibilities of disabled persons in building up their family life. Simultaneously existing regulations have been amended to acknowledge the social and family aspects of disability.

LEGAL PROVISIONS AND FACILITIES DIRECTED AT SOCIAL AND FAMILY INTEGRATION

Within the limits of this contribution it is hardly possible to review - even briefly - all existing facilities or provisions that promote the family life of the disabled. Such measures have recently been introduced concerning the different aspects of rehabilitation. The analysis of some of these measures leads to quite revealing conclusions.

PREVENTION

Prevention of disability has recently received increasing attention from policy-makers. This is a broad and rather unexplored field in which nevertheless priorities have to be determined. In some European countries genetic counseling centres and centres for preventive medicine have been created, regulated and subsidized, often on an experimental basis. The role of these centres is to inform and guide parents - especially disabled or high-risk parents - and to help them to prevent disability in their children. In some countries, e.g. in Belgium, legal problems have arisen concerning some aspects of prevention, such as preventive abortion, which is not legally allowed.

But even in countries where this legal problem is solved, alternative measures must be fostered , such as vaccination, early detection, early treatment, prenatal care, medical care for young children and at school, etc... Legislation concerning public health and social security can make an important contribution to the success of preventive actions. These contributions can take various forms : a preventive measure can be compulsory, can be a condition for granting a benefit, can be organized by the authorities or can be subsidized and controlled. Preventive policy should make an appropriate use of these legal instruments.

PSYCHOLOGICAL AND SOCIAL SUPPORT

Psychological aid to the disabled person and his relatives has been legally fostered by creating or subsidizing guidance centres, social aid centres, centres for marriage and family counseling and mental health centres. The effort towards the disabled in the field of social work and psychological aid is part of a general effort to compensate the loss of human contacts and human values in an industrialized and technological society (W.M. Hirs e.a. Hulpverlenen en veranderen, s.d., Van Loghum, Slaterus, Deventer).

As the traditional relation patterns disappear new social units are set up in which the disabled have to find their own place. The large family is replaced by smaller units that need support to assume their various functions.
Associations of disabled, parental associations and volunteers' work are the new expressions of solidarity. They don't replace the family, but they give the families social suport in their efforts to cope with disability. At the same time these organisations create possibilities for the emancipation of the disabled, as well for the individuals as for the families. Legal recognition of this evolution can be found in the subsidies granted to these associations, in the creation of participation structures (such as the National Council for the disabled) and in the delegation of some functions to these organisms, which can be legally designated to act as counsellors for the disabled concerning their rehabilitation, or to stand in court for them.

MEDICAL AND RESIDENTIAL CARE

Sickness insurance and public health regulations show a growing interest for the possibilities offered by home care and by the contribution of relatives in the care for the disabled. Without rejecting the positive aspects of institutional care, such as greater technical possibilities and guidance by skilled professional workers,

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rehabilitation policy nowadays tends to preserve the affective environment, the possibilities of participation and the individual approach, which are the specific values of family care. However the burden and stress put on the relatives should not prevent their own development.

To combine the advantages of both institutional and family care a variety of facilities have been created which provide care in a certain respect or for a certain time period : day-centres, night hospitals, rehabilitation policlinics, etc... To enhance the possibilities of staying at home for the disabled legal provisions have to guarantee the geographical distribution and accessibility of adequate facilities.

Financial support and other legal conditions must allow free choice for the disabled and his family (J. Kiers. Geen "deskundige" maar "gewone" hulp gevraagd. Klik, 5, p. 6-8, 1978). As a result of the former policy directed towards institutional care many rules tend indirectly to foster this care and hamper integrated family life. It is still rather common that institutional care is nearly completely supported by the state or other public organisms, whereas family care has to be supported largely by the family itself.

EDUCATION

In the same way educational facilities should grant the disabled and his family a fair choice between day-school education and institutional care. Regulations concerning as well normal as special education can't overlook the importance of the family for the education and development of the disabled child. It is not up to the law to decide what kind of education a child should receive nor to influence in any way the choice of parents or other responsable persons. Parents who want to keep their children at home should be entitled to the necessary help, including financial aid. To realize the free choice of parents, Belgian legislation provides that transport to the school or day-centre is organized or subsized by the state, that parents with a disabled person at home can receive help in house-keeping and that short-stay homes take care of the disabled child in case of emergency, e.g. when the mother is ill.

On the other side institutional care can be a valuable alternative required by the needs of the child or by the circumstances at home. Institutional care must be ruled to acknowledge parental responsibility, which remains after the admission of the child in an institution. Information, advice or even participation of the parents can develop the cooperation between the institution and the family. Regulations concerning the institutions can foster an evolution in this sense e.g. by making information or participation of parents a condition for subsidies.

PROFESSIONAL REHABILITATION

Professional rehabilitation and employment facilities can have an important effect on the family life of the disabled. The participation of the family in the rehabilitation program and the consequences of this program upon family life have often been neglected in the organisation and legislation concerning professional rehabilitation. Indeed, legislation should provide adequate guidance not only in the work situation, for the employer and the fellow workers, but also for the family of the disabled.

Reluctance of the relatives and lack of cooperation is often based on the fear of negative financial consequences resulting for rehabilitation. It is quite common indeed that allowances granted to a disabled person are stopped or strongly reduced as soon as this person, often after large and intensive efforts, is able to earn some income. This prohibition or limitation of cumulation of allowances and professional income constitutes an important obstruction towards rehabilitation.
Although unlimited cumulation can be unjustified, regulations should provide an intermediate system where an incentive for rehabilitation is preserved.

FINANCIAL BENEFITS

Cumulation rules constitute only one of the difficulties concerning financial benefits. (D. Lahaye, J. Van Steenberge en J. Viaene. Schade aan de mens, I, II en III., 1975-1977, Kluwer, Antwerpen). Allowances are not only depending on the income of the disabled but quite often the income of the husband, the wife or the parents is also taken into account. Such provisions leave the disabled completely dependent on his relatives. It can even refrain him from marrying and founding a family. This situation occurs when allowances granted to a single disabled person are withdrawn when the person founds a family and shares the income of someone else. Such regulations are a threat to the realisation of the right to normal family life.

The financial consequences of the disability of a member of the family must not be borne by this family but by society as a whole.

CIVIL STATUS

The protection of the right to normal family life must be laid down legally. The specific situation and needs of some disabled can justify the application of an adequate special civil status, such as extended minority or guardianship. However, such special status should not prevent personal and family development. Restrictions to freedom, to self-determination and the limitation of basic human rights must be severely controlled. Provisions corresponding to the situation of certain disabled persons cannot be extended to other groups. Severely mentally handicapped, psychiatric patients and chronically ill persons are confronted with different problems and should be treated in a distinct way.

The right to relationship - and especially to sexual relationship -, the right to marriage and the right to parenthood should be legally protected and should only be limited on behalf of prevailing values.
As rehabilitation policy moves towards integration and normalization, the disabled, their parents and other responsable persons are more confronted with these problems and the need for basic legal guidelines is increasing.

ENVIRONMENTAL AID AND INTEGRATING FACILITIES

In his contacts with other people and even in his contact with the facilities created to help him, the disabled person is hindered by barriers. Disability, in a sofisticated and competitive society, often leads to segregation and isolation. At more disability has a great influence upon the most diverse fields of human activity and problems can't always be solved by standard solutions. The disabled and his family have to deal themselves with these difficulties. To help them special efforts must be made and implemented by law in the field of social and administrative aid, adaptation of the evironment, housing and transport facilities, sports, leisure and cultural facilities.
A specific approach can be necessary to integrate the disabled and their family in such activities, and to stimulate their participation. The organization of special facilities and activities however should carefully be considered. Special facilities can better be adjusted to the needs and wishes of the disabled and are the expression of the solidarity among these persons, but they can also lead to labeling and segregation.

Legislation should foster as well the integrated as the specific approach, as both are complementary and must be used according to the given circumstances.
At more legislators must realize that the mere fact of enacting legislation concerning the disabled places the disabled and their families in a special and isolated position.

CONCLUSION

Rehabilitation, integration and emancipation are ideals that should not be applied only to the disabled person as an individual, but also as a member of a family and of a broader community. The full development of family life is only possbile, for disabled as well as for other persons, with the support of an adequate legal framework. Legal provisions can enhance the possibilities of family development for the disabled, but they can also have negative results. The efficiency of a regulation must be evaluated looking at its contribution to the welfare of the persons for whom it was made.

IDENTIFYING THE DIFFICULTIES CREATED BY PERSONAL HANDICAPS AND RELATING THEM TO THE NEEDS FOR CARE AND SERVICES.

MARGARET AGERHOLM *

ABSTRACT

Handicapped people are recognised **by** the difficulties which they experience in performance of those activities which are essential to their personal and economic independence - their personal autonomy.

Such difficulties can be identified for any individual by considering his performance in relation to these essential activities, of which 10 emerge as major headings on a check-list of difficulties which can threaten or destroy the individual's personal autonomy.

Identification of the difficulties under the 10 essential activity headings is the key to the provision of the correct (practical and appropriate) help for overcoming the difficulties experienced by people with personal handicaps.

A questionnaire, which draws a handicap profile of the individual's characteristics and resulting difficulties and which can be matched by a check-list of needs for help, is presented. Its application to casework records and to population surveys is indicated.

INTRODUCTION

Personal handicaps are those handicaps which result from disorders of the individual's own structures or functions. They are distinguished from "extrinsic" handicaps, which arise from disorders of his environment or circumstances.

The definitions of "handicap" and of its two broad divisions, intrinsic (personal) and extrinsic, are shown in Table I and the classification of intrinsic handicaps (with which we are concerned here) in Table II. They have already been published[1,2] and are shown here because they are the basis for this paper, and for the exercises for the identification of handicapped people, their difficulties and needs, in which I and others are currently engaged.

Handicapped people are recognised by the special difficulties which they experience in the performance of activities which are essential to their personal autonomy - that is to say, essential to their existence as separate, independent, individuals in human society.

Ten such essential areas of activity in which difficulties

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TABLE I
THE DEFINITIONS OF HANDICAP 1.2.

A handicap is a long-term disadvantage which adversely affects an individual's capacity to achieve the personal and economic independence which is normal for his peers

An extrinsic handicap is such a disadvantage arising from the individual's environment or circumstances

An intrinsic (personal) handicap is such a disadvantage arising from the individual's own characteristics, from which he cannot be separated

TABLE II

CLASSIFICATION OF THE PERSONAL (Intrinsic) HANDICAPS

(from "Handicaps and the Handicapped", J.Roy.Soc.Hlth 1975 p3)

KEY HANDICAPS		HANDICAP COMPONENTS
1 **Locomotor handicap** (the locomotor handicapped)	A	Impaired mobility in environment
	B	Impaired postural mobility (relation of parts of body to one another)
	C	Impaired manual dexterity
	D	Reduced exercise tolerance
2 **Visual handicap** (the visually handicapped)	A	Total loss of sight
	B	Impaired (uncorrectable) visual acuity
	C	Impaired visual field
	D	Perceptual defect
3 **Communication handicap** (the communication handicapped)	A	Impaired hearing
	B	Impaired talking
	C	Impaired reading
	D	Impaired writing
4 **Visceral handicap** (the viscerally handicapped)	A	Disorders of ingestion
	B	Disorders of excretion
	C	Artificial openings
	D	Dependence on life-saving machines
5 **Intellectual handicap** (the intellectually handicapped)	A	Mental retardation (congenital)
	B	Mental retardation (acquired)
	C	Loss of learned skills
	D	Impaired learning ability
	E	Impaired memory
	F	Impaired orientation in space or time
	G	Impaired consciousness
6 **Emotional handicap** (the emotionally handicapped)	A	Psychoses
	B	Neuroses
	C	Behaviour disorders
	D	Drug disorders (including alcoholism)
	E	Antisocial disorders
	F	Emotional immaturity
7 **Invisible handicap** (the invisibly handicapped)	A	Metabolic disorders requiring permanent therapy (e.g. diabetes, cysti fibrosis)
	B	Epilepsy, and other unpredictable losses of consciousness
	C	Special susceptibility to trauma (e.g. haemorrhagic disorders, bone fragility susceptibility to pressure sores)
	D	Intermittent prostrating disorders (e.g. migraine, asthma, vertigo)
	E	Causalgia and other severe pain disorders
8 **Aversive handicap** (the aversively handicapped)	A	Unsightly distortion or defect of part of body
	B	Unsightly skin disorders and scars
	C	Abnormal movements of body (athetosis, tics, grimacing, etc.)
	D	Abnormalities causing socially unacceptable smell, sight or sound
9 **Senescence handicap** (the senescence handicapped)	A	Reduced plasticity of senescence
	B	Slowing of physical or mental function of senescence
	C	Reduced recuperative powers of senescence

of performance can signify a threat to an individual's personal autonomy emerge as the areas on which scrutiny must focus in the identification of personal handicap in any individual and in any population group.

DIFFICULTIES OF PERSONAL AUTONOMY

The ten essential activities and the difficulties which can occur in each are shown in Section II of the Handicap Profile form[3]. (Table III) which has now had quite wide use in population surveys in the United Kingdom, as well as in various casework contexts.

Each area of activity heading is followed by an internal check-list of subactivities which distinguishes the various kinds and degrees of difficulty which can be experienced in that particular activity, with associated threat to the individual's autonomy.

Precise identification of kind and degree of difficulty experienced is important, since on them depends the significance of the difficulty in the context of handicap and the kind of need which it creates. Thus, difficulty in "getting out and about" has, in the past, too often been assumed to arise from locomotor disorders of the musculoskeletal group, with the expectation that it can be eased in most cases by provision of ramps and rails, wheelchair facilities, etc.. In fact, of course, this difficulty arises as or more often from disorders of vision, inadequate bowel or bladder control and severe exercise intolerance, each of which needs quite other kinds of help for easement of the difficulty.

Similarly, the significance of concurrent difficulties in different areas of activity will indicate the presence of more than one contributory disorder, with the possibility that the individual may not be able to take advantage of the more usual solutions for either separately. Impaired manual dexterity in association with visual difficulties, visual difficulties associated with locomotor disorders, for instance, seriously reduce the range of provisions which could ease one or other difficulty on its own.

THE HANDICAP PROFILE

This need to look at all of the person's difficulties simultaneously, and also to take into account other personal characteristics which determine the final choice of provision, demands that we not only collect all relevant information but also record it in manageable form. Human beings are complex organisms, and any assessment of needs must take into account this human complexity, which has been further increased by the addition of the handicapping disorder, to the original complexity.

Section I of the Handicap Profile provides us with the complementary information about the individual's character-

TABLE III
HANDICAP PROFILE FORM

SECTION I PERSONAL

Male/Female ☐☐

A. Code No. ________

Date of Birth D ___ M ___ Y ___

Date of Completion D ___ M ___ Y ___

B. HANDICAP(S)

Please state kind of handicap (e.g. deafness, difficulty in walking, weak or stiff hands etc.)

____

____

____

____

____

and causes (if relevant) e.g. a diagnosis, like arthritis, multiple sclerosis, amputation etc.; or "ageing"

____

____

____

____

____

____

C. MOBILITY CHARACTERISTICS

Tick most appropriate group

1 Normally ambulant ___
2 Ambulant but restricted ___
3 Ambulant with aid (stick, frame etc.) ___
4 Ambulant only with fitted appliance ___
5 Ambulant only with artificial limb ___
6 Walks but falls ___
7 Walks but needs guiding or personal support ___
8 Walks but cannot stand/sit unaided ___
9 Wheelchair user ___
10 Wheelchair bound ___
11 Bedbound ___
12 Other ___

*COMMENTS OR ADDITIONAL INFORMATION ON ANY PART OF QUESTIONNAIRE

____

____

____

____

____

____

____

____

____

____

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SECTION II DIFFICULTIES EXPERIENCED

DO YOU HAVE DIFFICULTY WITH (tick appropriate items)

A. GETTING OUT AND ABOUT ? ☐

1 Getting in and out of house ___
2 As pedestrian ___
3 In shops etc. ___
4 On public transport ___
5 As self-driver ___
6 As car passenger ___
7 As cyclist ___
8 As wheelchair user ___
9 Because of severe fatigue ___
10 With parking ___
11 With toilets ___
12 Finding way around ___
13 Using guide dog ___
14 Emotional problems ___
15 Behaviour problems ___
16 Special risks ___
17 Other (state)* ___

B. MOVING AROUND AT HOME ? ☐

1 Stairs ___
2 Steps ___
3 On level ___
4 Doors and passages ___
5 Seeing things in way ___
6 Finding way around ___
7 Falling ___
8 Sit/stand, stand/sit ___
9 On/off bed ___
10 In/out garden ___
11 Using switches, windows etc. ___
12 Reaching and picking things up ___
13 Other (state)* ___

C. COMMUNICATION ? ☐

1 Hearing ___
2 Talking ___
3 Writing ___
4 Reading ___
5 Answering door ___
6 Talking with strangers ___
7 Talking with family ___
8 Using telephone ___
9 Contacting G.P. and other services ___
10 Getting help in an emergency ___
11 Other (state)* ___

D. HOME CARE ? ☐

1 Light cleaning ___
2 Thorough cleaning ___
3 Light kitchen work ___
4 Major kitchen work ___
5 Bed making ___
6 Washing (laundry) ___
7 Minor repairs ___
8 Decorating and maintenance ___
9 Cleaning windows ___
10 Garden care ___
11 Shopping ___
12 Other (state)* ___

E. FAMILY CARE (other than of unhandicapped spouse) ? ☐

1 Child care at home ___
2 Nursing of sick child or relative ___
3 Escorting family ___
4 Supervising family activities ___
5 Communicating with and for family ___
6 Other (state)* ___

F. SELF CARE ? ☐

1 Getting up (dressing and toilet) ___
2 Going to bed (undressing and toilet) ___
3 Using toilet ___
4 Washing all over/using bath ___
5 Foot care ___
6 Feeding and drinking ___
7 Preparing own food ___
8 Altering position in chair, bed, etc. ___
9 Weak (leaking, etc.) bladder ___
10 Weak (leaking, etc.) bowel ___
11 Other (state)* ___

G. SPECIAL SELF–CARE NEED ? ☐

1 Taking prescribed medicine(s), injection(s), etc. ___
2 Managing appliances (calipers, trusses, etc.) ___
3 Managing discharging sinuses, colostomy and other surgical openings ___
4 Managing incontinence (uncontrolled bladder or bowel) ___
5 Managing epilepsy ___
6 Need for special precautions e.g. bleeding, fragile bone diseases, risk of pressure sores etc. ___
7 Dependence on machines e.g. respirator, kidney machine (state) ___
8 Other (state)* ___

H. SELF ORGANISATION ? ☐

1 Mental retardation or other intellectual defect ___
2 Emotional disorder ___
3 Behaviour problem ___
4 Memory disturbance ___
5 Space or time confusions, etc ___
6 Danger to self or others ___
7 Reduced consciousness ___
8 Reduced responsibility e.g. leaves gas on, wanders off ___
9 Other (state)* ___

I. EMPLOYMENT (because of handicap) ? ☐

1 Finding suitable work ___
2 Transport to and from work ___
3 Premises at work ___
4 Communication problems at work ___
5 Fatigue ___
6 Unwelcome ___
7 Need time off (sickness) etc. ___
8 Other (state)* ___

J. EDUCATION (because of handicap) ? ☐

1 Transport ___
2 Premises ___
3 Special education needs ___
4 Special help needs ___
5 Unwelcome to staff ___
6 Unwelcome to fellow students ___
7 Other (state)* ___

K. OTHER ACTIVITIES (state) ? ☐

________ ___

________ ___

________ ___

________ ___

TABLE IV
SECTION III FORM (Health and Welfare Needs)

SECTION III HELP NEEDED AS RESULT OF HANDICAP (Services and equipment)

Tick "Has" if has and is satisfied. Tick "Wants" if has not, but wants. Tick "Has" and "Wants" if has, but is not satisfied; e.g. service inadequate, equipment is broken or its service is unreliable.

A. PERSONAL HELP AND SERVICES

	Has	Wants
1 Shopping		
2 Collection of pension		
3 " medicines		
4 " other (state)*		
5 Library service		
6 Occasional transport		
7 Home help		
8 Meals on wheels		
9 Laundry service		
10 House maintenance		
11 Garden maintenance		
12 Social outings		
13 Visitors		
14 Better contact with G.P.		
15 District nurse		
16 Health visitor		
17 Physiotherapy		
18 Chiropody at home		
19 Chiropody at clinic		
20 Services for the deaf		
21 Services for the blind		
22 Speech & communication training		
23 Social worker		
24 Occupational therapist		
25 Other (state)*		
ADVICE ON:		
26 cash benefits, rebates, etc.		
27 services		
28 aids and equipment		
29 mobility		
30 education		
31 employment		
32 holidays		
33 recreation		
34 housing		
35 own disorder or handicap		
36 special voluntary organisations		
37 other (state)*		
REGULAR PERSONAL HELP FOR:		
38 mobility in house		
39 dressing		
40 toilet		
41 bathing		
42 foot care		
43 feeding		
44 injections		
45 surgical dressings, etc.		
46 appliances		
47 other (state)*		
FREQUENCY OF HELP NEEDED:		
48 less than once a week		
49 once a week		
50 twice a week		
51 once a day		
52 twice a day		
53 through the day		
54 in the night		
55 other (state)*		
SPECIAL CENTRE NEEDED:		
56 Centre attendance (day, occupation/work centre)		
57 Sheltered work		
58 Hostel facility		
59 Sheltered housing		
60 Residential care		
61 Other (state)*		

B. EQUIPMENT OR ITS MAINTENANCE

MOBILITY	Has	Wants
1 Mobility aid outside the house (stick, long cane)		
2 Guide dog		
3 Mobility aid inside the house		
4 Ramps and rails outside house		
5 Ramps and rails inside house		
6 Special handles, switches, etc)		
7 Lift between floor levels		
8 Hoist (floor, ceiling etc.)		
9 Wheelchair, push		
10 Wheelchair, self propelled		
11 Wheelchair, motorised indoor		
12 Pedal tricycle		
13 Motorised tricycle ("Invacar")		
14 Motorised wheelchair (outdoor)		
15 Car or van		
16 Car or van modification		
17 Exempt from Vehicle Excise Duty		
18 Orange badge for parking		
19 Garage or garage modification		
20 Cash help with mobility needs		
HOUSING AND HOME FACILITIES		
21 House modification or addition		
22 Rehousing		
23 Household appliance (heating, laundry, etc.)		
24 Kitchen aids or modifications		
25 Bath aids or modification		
26 Shower aids or modification		
27 Toilet aids or modification		
28 Commode		
COMMUNICATION		
29 Hearing aid		
30 Voice magnifier		
31 Telephone or telephone adaptation		
32 Typewriter		
33 Communication board		
34 Visual magnifier		
35 Large print book		
36 Talking book		
37 Braille equipment		
38 Call or alarm system		
39 Control system		
PERSONAL EQUIPMENT		
40 Aids for dressing		
41 " reaching		
42 " feeding		
43 " other (state)*		
44 Special clothing		
45 Special footwear		
46 Elastic stockings		
47 Truss, brace, corset, caliper, etc.		
48 Artificial limb		
49 Bedpan		
50 Urinal (bottle)		
51 Fitted external urinary appliance		
52 Catheters, collecting bags for bladder, etc		
53 Fitted bowel appliance (including colostomy, etc.)		
54 Absorbent pads		
55 Waterproof bedding etc.		
56 Waterproof clothing		
57 Soiled laundry facilities		
58 Disposal system for dressings, absorbencies, etc.		
59 Special life machines e.g. respirator, kidney machine, aspirator, pacemaker, oxygen etc. (state)		
60 Other (state)*		

istics which explain and determine the significance of his difficulties. This information is both non-specific to handicap, viz, age and sex; and specific, viz, his basic disorder of function, (lame, blind, etc) and, where known and relevant, the diagnoses underlying his disorders (cerebral palsy, Parkinson's disease, amputation of limb(s) etc. and information on one particular characteristic; his mobility or immobility, presented as a check-list.

NEEDS FOR CARE AND SERVICES (Table IV)

An individual's handicap profile, concerned as it is with his permanent personal characteristics and the difficulties these can create for him in the acquisition and maintenance of his personal autonomy, shows little change over the years, apart from a tendency for difficulties to decrease slightly with maturity if present in childhood, and to increase with senescence. But the individual's needs which result, whether viewed by himself or by others, can vary according to the context in which they are considered. For this reason Sections I and II have a wide application, while the application of Section III's, recording the individual's resulting needs, tends to be narrower, directed to use in specific contexts.

The Section III shown in Table IV has been designed for use in Surveys of population groups undertaken to discover the needs of handicapped people for health and welfare provisions. Other Section III's can be prepared in the context of handicapped people's needs in education, employment, residential care, etc., and these Sections can be matched with the basic Handicap Profile drawn by completion of Sections I and II. This means that the repeated assessment of the individual's characteristics and difficulties, which has been a serious problem for assessor and handicapped person alike and which often demands more knowledge for successful completion than the assessor can offer, is no longer necessary. The handicap profile becomes the handicapped person's passport to the services and other provisions to which his difficulties entitle him, It is important that he possess for his own use a copy of the profile, which is as useful to himself as to any other individual or to any authority.

CONCLUSION

Accuracy in these documents is helped by the format of check-lists which demand no verbal effort for the description of difficulties and needs and do not depend on over-specific YES/NO decisions (only positive response is recorded) or, vague gradings of severity of difficulties or needs. They draw in the features of a profile, and usefully facilitate internal validation between the Sections.

Finally, the use of check-list items, each of which to/which only one response is possible allows the information to be stored on punched cards or computer records without intervening interpretation. This means that general information harvests obtained in Surveys can be supplemented from casework records using the same form, so that there is reciprocal benefit between casework and Surveys.

References 1. Agerholm, M., J.Roy Soc. Hlth. 1975 p.3
2. Agerholm, M., J. Med.Leg.Soc. 1975.
3. Agerholm, M., Blake, N. Cooke, K. OUTSET Report on City of London Survey, 1976. London.

FINANCIAL PROVISIONS FOR DISABLED FAMILIES

Mrs Jean Simkins*

"A family that includes a disabled person becomes a disabled household". Some aspects of financial disabling in such families, and the cash benefits structure in the UK, are discussed. The system is intended to assist disabled families, yet for many, their financial struggles are *still* more difficult than those of their neighbours, even in generally struggling communities. The basis of the system is related to a mixture of underlying principles - insurance, relief of destitution, compensation and provision for old age. There is no adequate recognition of the extra costs of disablement. Interference tends to be more in evidence than independence. Problems arise for those who could work part-time or intermittently. The cost to a family of a disabled homemaker is still a matter of contention. Complexity costs the disabled millions of pounds in unclaimed benefits. Conclusion: there is still much to be done.

"A family that includes a disabled person becomes a disabled household". Those are the words of Alf Morris, now Minister for the Disabled (*No Feet to Drag*. 1972. P.29) - and one critical factor in such disabling is very often finance.

In December I was fortunate enough to take part in a United Nations expert group meeting on economic aspects of rehabilitation. I heard there a story I want to pass on to you now. (To my infinite regret, I cannot really do justice to it - you must imagine it told by an elderly gentleman of generous proportions and enormous humanity, who has a large family of his own and an immense wisdom and kindliness, and who has spent many years bringing into being a rehabilitation service in a country which is both tropical and poor.)

He was once faced with the problem of how to rehabilitate a man, paralysed from the waist down and dependent on a wheelchair, whose family lived in a remote village where the only means of livelihood for those without special skills were growing crops on the small plots of cleared land, or taking produce to the nearest market. The terrain was a mixture of jungle and rocks and both occupations were clearly inappropriate for a man in a wheelchair. After talking to the man, and the village elders, it emerged that virtually every household grew maize and every household pounded its own coarse flour to make the tortillas which are a standard part of the diet. So a small hand-mill was bought, and the man taught how to use it, and it was agreed that villagers would bring him their maize for grinding, and pay him for the service, in cash or in kind.

Later, going back to see how he was getting on, they were astonished at the success of the venture. Not only was he supporting his family - and to a better standard of living than they could ever have hoped for when he was fit - but the man had become the hub of the community: everyone came to him bringing their grain ... and their gossip. He knew all that went on, and was respected, and his advice sought, as a man of experience. He was a happy and a busy man.

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Sadly, he was so happy, and so busy, that he forgot the warnings he had been given: a neglected infection got out of control, and he died.

Now, it was never the practice of the authorities to give equipment to people they rehabilitated (they had found from experience that relatives were apt to sell it in emergencies!). It remained officially "on loan". So, when they heard of his death they sent a man to the village to bring back the hand-mill. Chaos! The villagers were horrified. They said "you can't take away the mill - it has changed the whole pattern of our community. Not only here, but in other villages nearby, nobody pounds their own maize any more. And now you want to take it away?"

Puzzled, the official said "surely, now the man is dead, it is not being used?" There was great dignity and a certain scorn in the reply: "He had a ten-year-old daughter. We gave it to her and she is now supporting the family."

The mill was allowed to remain - a form of "death benefit" rare in its genuine usefulness.

That story may seem to belong to a different world, but many things about it would strike a chord of recognition among disabled families in our own community: the impact on the whole family's way of life of the disablement, and then the rehabilitation, of the breadwinner; the passionate desire to be self-supporting, independent, and have a place in the community; the fact that the right help can achieve this at relatively little cost. It would have been very easy to spend much more in an inappropriate way and waste it all if the approach to the problem had been less sensitive.

Handicapped families would also appreciate - perhaps somewhat wistfully - the sensitivity of that official help, first, in understanding the background; in consulting with those involved and having the imagination to devise the scheme.

Notice they are quite realistic about human nature, with their insistence on loaning equipment. But notice also the flexibility of the official response to the villagers' action in giving the mill to the daughter - it is not hard to envisage a system which would have said "you can't do that - it's not in the rules!"

I would like you to keep that story in mind in considering the good and the bad about cash benefits for handicapped families in the UK today.

Perhaps I should also point out that I know the subject not only from the economic standpoint, but also from that of the consumers, having started my family while sharing the struggles of a severely disabled husband, and as a consequence having had among my close friends, over the past fifteen years, many other families with a handicapped parent or child, or even both.

Let us look first at the good news. The UK system of cash benefits is intended, especially since the Chronically Sick and Disabled Persons Act, the appointment of a Minister for the Disabled, and the efforts in recent years to improve the Supplementary Benefits scheme, to assist all such families. Its provisions should theoretically, in one way or another, reach handicapped wage earners (or male heads of household who would otherwise be the breadwinners) and their dependants. Single parent householders, themselves handicapped (or their children), should also be covered, and most benefits, be they age-related or arising from industrial or services injury or sickness, carry additional allowances for dependants. Finally, Supplementary Benefit was intended to provide a safety net for any who fall through the rest of the system.

So why is it that when locating the homes of disabled families the unpainted house, the overgrown garden, are so often the first of many signs of financial struggles more difficult than those of their neighbours, even in a generally low-income area?

To begin to understand the present situation it is essential to remember that the "system" we have is not something that was designed and constructed for the job it is doing. A patchwork of provisions has grown up, based on a mixture of principles. Central to the present system is the insurance principle, under which what you get is affected by what you have been able to contribute in the past. This, however, was grafted on to provision for the (often patronising) "relief of destitution"- which was much older. The extension of the idea of compensation, first introduced by War Pensions, into civilian industrial injury benefits brought yet another principle into the mix.

And the bad news? The resulting structure does not deal with disablement or handicap as such - only as an incidental aspect of poverty, or interruption of earnings, or of having reached the particular point on the calendar designated as "retirement age".

Another of the basic problems is that there is no adequate or coherent financial recognition of the unavoidable extra expenses of disablement. I am not, now, speaking of those costs which are recognised by Supplementary Benefit regulations, such as extra bed linen for incontinence, extra heating bills (though even for these the "recognition" may be woefully inadequate for the extra cost). Extra costs for the disabled person include getting someone else to do all the things he or she can't do: the cost of paid help to do every little do-it-yourself job in the house and garden (this is"saved"when the jobs are not done - hence the visible signs I spoke of earlier); the cost of paying others to collect, escort, or care for children; the extra expense of not being able to "shop around" but having to pay the higher prices of the nearest shop and the specified item, in order to save the Home Help's precious time (rather than the cheapest shop and the change of intended menu open to householders shopping for themselves); and the item-by-item cost of mobility, never remotely guessed at by those who can use their own feet and public transport or who have transport of their own.

In 1976, commissioned by the Disablement Income Group, the Economist Intelligence Unit carried out a study, published earlier this year under the title "Whose benefit?" We used the files of DIG as our starting point, but also drew on the experience of welfare rights workers, social services staff and researchers - any who were in touch with handicapped people - up and down the country. Our report includes many examples given to us by them. There were families whose financial problems had mushroomed over three or four years on an income never designed for long-term support, because the law says that if eligible for more than one benefit, they must be paid the higher, and a few pence difference had prevented them ever getting started on the two-year qualifying period at low-rate Supplementary Benefit and thereby reaching the substantially higher long-term rate. The only "solution" offered had been to dub them "problem families" and send in a battery of social workers, when the most basic need was for an adequate income.

Many people felt that, although staff on the ground may work together quite well, there is a need for a system which really dovetails the services of local authorities with the cash benefits available from central government. At present they sometimes overlap, sometimes conflict, and occasionally leave gaps across which the disabled family is helplessly passed back and forth.

Sometimes the result is top-heavy administration. One man, who only wanted four door-handles of a particular type, wrote wistfully that if he had had the money he would have bought them, but that required resources either to get to shops or to telephone suppliers, as well as to pay for the handles themselves. They were "available" through the local authority, but at a cost in delay and administration which is out of all proportion to the items needed.

There is a whole category of people who struggle to carry on working, but unlike the man with the hand-mill, they find themselves hindered by the system... like the mentally handicapped 36-year-old who had lived on Supplementary Benefit (or its equivalent) since he was 16. His day centre instructor found him a job, in the belief it would help him. For fifteen weeks he managed to cope, but then he became ill. When he gave in and re-applied for his Supplementary Benefit he was given the significantly lower short term rate - as though this were some new illness - because the period of employment had exceeded thirteen weeks. True, when his case was taken up, the Supplementary Benefits Commissioner said such cases would now be "looked at more sympathetically" but that is waiving the rules, not making them more appropriate.

The recent news that a comprehensive disability benefit is being actively considered makes it imperative to draw attention to the need to incorporate into any new scheme more realism regarding handicapped people. The present system does not acknowledge in those of working age anything between "sickness" (which qualifies for the appropriate benefits) and "fitness"(when benefits depend upon "availability for work"). A person quite significantly handicapped, e.g. by cerebral palsy or the after-effects of childhood polio, may be advised to go on to sickness benefit even if seeking work, because this relieves him of the often-expensive obligation to visit the employment offices regularly. But if he does this, he is technically no longer"available for work" and experience suggests he will tend to be overlooked for job opportunities. Perhaps more serious, he is creating a false impression of his own health record for possible future employers, and the doctor's written declaration that he is sick is an expedient nonsense which some doctors may, with every justification, object to signing. Officials, doctors and the handicapped person are all obliged to put themselves in the wrong because the system does not recognise that one may be fit and yet still handicapped.

The same shortcoming in the system causes some people who have made great efforts to re-train as their disabilities have increased, to find they cannot take work they could manage (for example, on a part-time basis), because of the economic effect upon their families. By so doing they would not earn enough to support the family, but they would earn enough to cut off their entitlement to benefit.

Since we finished our study, attention has been focussed on the housewife's Non-Contributory Invalidity Pension. Leaving aside the actual demands on the family budget for special needs derived directly from her disability, the costs to a family of a disabled mother and marriage-partner arise in the most practical ways - the fetching and carrying, cooking and cleaning, washing and mending and "making do", escorting and chauffeuring, gardening and secretarial functions, among others, not performed. Who pays bills at offices that are never open when a worker is at home if his wife can't go out alone? Or takes things to the cleaners or repairers (other than on a Saturday, the busiest day, implying in itself an uneconomic use of the fit partner's already over-committed time)? Or makes arrangements with gas, electricity or other services if there is no telephone and the housewife cannot go? Yet the decision whether to pay this benefit depends on proof of inability to carry out "household duties" narrowly defined and recently argued in a court of law in terms of how much sugar a woman can lift. Not, you will notice, whether she can safely walk about while carrying it, or cook with it - other than in a step-at-a-time fashion. That takes far longer than for someone who can pour things into a bowl with one hand while stirring with the other - and turn quickly if something boils over while she is so doing. The concept is both impractical and humiliating, but the real shock was for those who succeeded in qualifying, despite this rigmarole, and then found they were no better off, or a few pence only, precisely because they were worse off to start with. Those whose husbands are earning, whatever the salary, receive the full allowance. For those whose husbands are on state benefits - such as the many who are at present suffering unemployment - only the difference between the appropriate dependant's allowance and the new housewife's benefit is payable. Yet the act of qualifying for HNCIP proves that they have expenses not incurred by the ordinary "dependant" who, under the rules for unemployment benefit, could actually be earning and contributing to the family's resources.

Moreover, because it is so contentious, the HNCIP has again high-lighted the cost to the client involved in repeated applications, medical examinations and appeals. The complexity of the system and the futility people see in having to battle for their theoretical entitlement only to find that it is of little real benefit, lead to millions of pounds remaining unclaimed. Do not be misled, however: apart from the question whether we really want to economise by making the benefits so troublesome and so trifling, or the procedures so humiliating, that people do not take them up, as a community we do not in this way escape the cost. It may frequently be more in the long run, when the result is the break-up of families or greater dependence on expensive professional care services, themselves already overstretched.

Our conclusion was that the addition of more minor changes only adds to anomalies, administrative problems and the confusion of the people intended to benefit. A complete renewal is required. The only time the British benefits system has come near to this was in 1942, with the

Beveridge report. We need a new Beveridge, to produce a system of support that is purpose built to meet the real needs of handicapped people and their families with something of the sensitivity and flexibility reflected in our original story.

We also believe that the early stages of such a new scheme must include (a) a change in the rules concerning fitness and work; (b) must provide for the unavoidable extra costs of disabled living; and (c) must adapt to the changing role of women in our society.

Until we achieve this, families will continue to carry the double burden of economic disablement and the disabilities of individual members.

Seminar 2

EMPLOYMENT

Chairman: *Mr. T. Jeffries*

The Family and its Role in Decision Making regarding Occupations for the Disabled

Prof. Dr. sc.med. Ursularenate Renker

An Approach to the Employment of Disabled People in Britain

Dr. Silvester

GENERAL

Chairman: *Dr. C. D. Evans*

Disability in the Family

Dr. Ann Raikes

Disability in the Family—The Changing Scene

W. H. Laming

EDUCATION

Chairman: *Mrs. M. C. Clark*

Access to Higher Education is by Attitudes rather than Architecture

Miss Judy Crosby/David Spooner

The Rutland Street Project

Mr. Seamus Holland

PSYCHOLOGICAL

Chairman: *Barbara Ridsdale*

Psychological Response to Illness and its Effects on the Outcome of Occupational Rehabilitation

Charles Burdett/Christopher Olsen

The Problems and Challenges in Taking Care of the Elderly Disabled—The Case of the Single Caring Daughter

Miss Heather McKenzie, LL.B.

THE FAMILY AND ITS ROLE IN DECISION MAKING REGARDING OCCUPATIONS FOR THE DISABLED

Ursularenate Renker

Families represent the smallest cell of the human community. Comprehensive sociological and psychological studies have covered issues arising from the inter-relationships between the family and its environment and the sphere of human relations inside the family.

All results point to the importance of the family, the paper by Renker et al. provided detailed information.

In our paper we want to look at the interrelationship between the family and an occupation for a disabled member.

For centuries the views held by family members of various trades have been a factor to be reckoned with. Differences can be found, depending on the type of social order, and although they are qualitative in nature, they tend to confirm our initial hypothesis.

What is called choice of a profession has been conditioned by the family's social position and habits, the economic situation surrounding its residential area and the number of children. This still holds for many countries. Tradition had it who would take over the farm, the craftman's workshop or any other enterprise. It was an exception if the parents did not get their way, something that can be proved by a good number of examples. But today we should not reflect on history but rather analyse the situation at present and make suggestions. We only wanted to make clear that we are not raising something new. But under all systems, consideration has to be given to the situation of society as a whole, i.e., social order and economic state of the country concerned.

Over the last few decades, family influences on the choice of a profession or trade in the developed industrialised countries have undergone changes. But as borne out by analyses, the opinion held by parents still is a determining factor in this respect.

It has been and is very often claimed that young people lack mental maturity to arrive at a well-founded decision. This is something one cannot fully agree with, before all when considering that it is compulsory to attend ten years of schooling in the German Democratic Repablic. 16-year olds have ideas of their occupation and in addition, they have gained insights during compulsory polytechnical instruction.

Prof Dr sc med Ursularenate Renker
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Martin Luther University Halle-Wittenberg - DDR

Sometimes the choice is made difficult because of lack of knowledge of available opportunities. But in this country this is always attributable to neglect on behalf of young people or their parents who made insufficient use of given chances. Thus, every district has its vocational guidance centre, larger enterprises have their own consultation centres; there is a wide range of literature, radio and television provide comprehensive coverage.

There is no unemployment in the GDR, which means that all school leavers will be given either an apprenticeship or a place at a university or college.

Finding the appropriate profession or trade is a problem of particular urgency facing disabled youth. The greatest obstacles arise from misconceptions about the abilities and capacities on behalf of the young person on the one hand and the requirements of a prospective profession or trade on the other.

In the final analysis, every young person wants to take up some particular work and a decision on whether this is practicable can only be made after considering all pros and cons of the case in point.

Following ODE the following criteria must be considered and there must be a positive outcome in all four:

(1) physical capacity to cope with the prospective occupation;
(2) intellectual ability to cope with the prospective occupation;
(3) by his character, the person must be able to cope with the prospective occupation,

and

(4) after the course of studies or training, an appropriate job or appointment must be available near the place of residence.

In this respect you might be interested in the results of an analysis carried out by Mrs Hein of 276 applications for a place in the rehabilitative occupational training centre. The analysis showed that 152 people undergoing rehabilitation (i.e., 55.06 per cent) had made their choice, whereas 124 (i.e., 44.9 per cent) did not give any preference. Only in 49 cases did the choice tally with the decision made after taking advice. From these findings the author derived the conclusion that both the quality of information and guidance for the disabled must be improved.

For this purpose it is not only necessary to strengthen cooperation between the special schools for disabled children and youths, rehabilitation committees, and centres for occupational rehabilitation, but there also has to be participation by parents over a longer period.

For well understandable psychological reasons very often parents will not be able to give an objective evaluation of their disabled child, therefore we think that good contacts with the school are essential. At every school in this country there is one teacher whose task is to provide careers guidance and parents may seek early advice. If possible, contact should be established as early as in the 4th or 5th form, so that the capabilities and capacities may be under continuous observation and purposeful control. It should be clarified as early as possible which occupation is out of the question and which might be considered.

In this respect, the outcome of continuous medical checks by the youth doctor responsible is important, too. In a decree promulgated in autum 1977, provision has been made for an early distribution of apprenticeships in particular to the young disabled. This is combined with timely medical fitness checks.

This short description was to show efforts made in the GDR to enable parents to have constructive and clarifying talks with their own child.

It is quite normal for young people to have varied interests, and it makes sense to find out those which are or might be relevant to a future occupation. Extra-curricular work done after school might help in this respect, such groups do courses on woodcraft and on textiles or clay, there are also groups for photography and other specialised interests such as chemistry, physics, mathematics and German, to name just a few.

Part of the duties faced by parents is to prepare their children for future work, this is a general and non-controversial demand.

But as for other general demands it is quite easy to agree but remains an outstanding problem how to meet them.

We want to attempt to provide some practical hints to help in this field. We assume that the family is stable and that the parents have the intellectual capacity to cope with the educational challenge raised by their cooperation in preparing for a future occupation.

We did already point out that there are opportunities for parents to get full information on all trades and professions. It is an interesting feature, however, that parents mainly guide their children in the direction of traditional professions or trades. Definitely, there is a basic attitude at work that causes considerable problems. Every one working knows that it is necessary to think about improving on one's qualifications. The scientific and technological revolution introduces permanent change into all spheres of economic and public life and one has to cope with this to be able to do one's work and apply the latest scientific standards.

But in most cases, children are brought up without the educational level required. There is no dearth of literature, papers will be read and radio and television make all efforts to disseminate knowledge. But the decision of whether or not they want to acquire educational knowledge is left to the parents themselves. The same applies to knowledge of the occupations available and we have to make stronger appeals to parents to be aware of their responsibilities.

But purposeful advice on possible careers is only part of the parental duties.

Essential features include the bringing about of a positive attitude to work, to discipline, as well as independence, devotion and responsibility.

Very easily, the disabled child will be given a special place in the family, may be, because the parents spoil him, clear away all obstacles and are always on call. The other extreme of that special position is that the child is neglected and in the way, and always feels that he is superfluous. Both extremes are no good.

Integration of a disabled child must be brought about in the family, the issues involved are treated elsewhere. The bringing about of a positive attitude towards work means that both parents and young people understand that there is no particularly valuable occupation or one that does not deserve respect. But there has to be a guaranteed chance for everyone to use his capabilities and capacities. To explain I would like to refer to an example from the health system: No surgeon can do complicated operations unless there are nurses to cooperate; success of any treatment can only be guaranteed if there are hygienically unobjectionable conditions in the room and whole of the ward. Regrettably we have to experience all too often that parents advise mentally deficient young people not to do cleaning work.

We would like to state: every bit of work is valuable and necessary, any moral value judgment harm society.

This basic attitude must be reflected in the evaluation of work done in the home. Every job needs doing and even the best meal will not taste, if plates and cutlery are dirty.

There must be education to discipline for disabled young people, too. They have to take their role in the family and all jobs, be they ever so small, must be done in time and properly. Fixed times for getting up, meals and going to bed must also be kept by the young disabled.

The bringing about of an independent attitude must take place in the family before all. Depending on the degree of disability a child a young person must learn to keep himself clean, to eat alone and to move in the streets, to name just some examples.

In general, there are successful attempts by rehabilitative departments to bring about this independence. But family members then must not misunderstand assistance and do everything for the young person.

The promotion of devotion and responsibility are parts of preparing for an occupation, too. Daily family life provides enough chances of doing something for somebody else and to share responsibility for harmony.

The distinctive character features outlined will be needed for work in a profession or trade to achieve integration, something so very vital for a disabled person. They are acquired in the course of life. It is important to start early to set up a good foundation for a working life.

In the course of professional training, whether this be in a factory or in a rehabilitation centre, priority will be given to knowledge of the chosen field.

It is a matter of course that every educator worth his salt will strengthen these moral features, but the ground should have been laid in the family, otherwise life will be even more difficult for the young disabled.

There is one more aspect to consider.

A family atmosphere, joint talks or duties, pleasure and success at work are important for the development of young people. It is harmful for their personality development if parents and other members of the family only refer to negative experience which is always there.

Sharing experience with his parents, a young person has to learn that without work, without some type of productive activity, life will lose much of its essence and that work raises the joy of life and general well-being.

Through their education the parents must provide a basic awareness in a young person so that he realizes: My work contributes something to society, I am a part of society and society also stands by me.

AN APPROACH TO THE EMPLOYMENT OF DISABLED PEOPLE IN BRITAIN

R.A. SILVESTER , M.A., Ph.D., M .I.P.M., PERSONNEL DIRECTOR, REMPLOY LTD.

I have been asked to speak to you today about the employment of disabled people in this country as it is handled by a unique organisation known as Remploy Limited. The organisation is quite complex and in the time available to me I must content myself with telling you something of the background of the company and of its method of operation.

The company was set up in 1945 under the provisions of the Disabled Persons (Employment) Act, 1944 to provide purposeful employment for severely disabled people under conditions which are compatible with the needs of disabled people. I think it is important to go back to the Act for the definition of a disabled person, which in the Act is "a person who, on account of injury, disease or congenital deformity is substantially handicapped in obtaining or keeping employment,or in undertaking work on his own account, of a kind which apart from that injury, disease or deformity would be suited to his age, experience and qualifications." The 1944 Act also made provisions for the establishment of a Register of Disabled Persons and for the setting up of the National Advisory Council on the Employment of Disabled People and the Disablement Advisory Committees, which give advice to the Secretary of State for Employment on matters relating to the employment of disabled people. The Disabled Persons' Register is divided into two sections - 1 and 2 - and it is from the latter, which is made up of people who require sheltered employment, that Remploy recruits its workforce.

The method of recruitment is through interview panels arranged by the Factory Manager and the local Disablement Resettlement Officer and the interviews are attended by the Factory Doctor and usually also by the Area Personnel Manager. The prospective employee has usually been given the opportunity of seeing the work being carried out in the factory before the formal interview and the interview itself takes the form of reviewing the applicant's employment history, and medical history, and trying to form a judgement as to whether the person will be suitable for employment in the Remploy environment. All engagements are subject to three months' trial period and as a general guide the company's criterion of ability is that a disabled person should be capable of approximately one-third of 'normal' output.

The company at present employs just under 8,000 disabled people in 87 factories throughout England, Scotland and Wales. To give some idea of the role of Remploy in the employment of disabled people, there were at March, 1977 13,345 people in various forms of sheltered employment. Of these 7,972 (nearly 60%) were employed by Remploy. At Appendix I the growth of the company in the last 10 years is shown. It will be seen from these figures that sales have risen from £8 million in 1968 to nearly £25 million in 1977. In the current financial year the company expects its sales to be in the region of £29 million, and the number of disabled people employed to be well over 8,000. Because of the unique nature of the company I should perhaps at this point say that the difference between the cost of running Remploy and the revenue it generates by its manufacturing and sales activities is met in the form of a subsidy from the government.

The disabled people employed by Remploy cover a very wide range of physical and mental disabilities, as shown at Appendix II. It will be seen that the biggest single category is mental sub-normality, closely followed by psychoneurosis and other mental illnesses. This is a growing problem involved in the employment of disabled people in an industrial working environment and is one of which the company is very conscious.

It would, I think, be helpful if I said a little about the organisation structure of Remploy. The company's Board of Directors is appointed by the Secretary of State for Employment and consists of a number of non-executive directors representing industry, trade unions and local authorities, and seven executive directors, including the Managing Director. A simple organisation chart will be found at Appendix III. As will be seen from the left hand side of the chart, the company's manufacturing activities are divided into three groups, each headed by a director. The Furniture Group covers domestic furniture, office and institutional furniture and shelving, mainly for libraries. The Leather and Textile Products Group covers travel goods, protective clothing, fashion knitwear and orthopaedic equipment. The Packaging and Assembly Group provides a wide range of packaging and assembly services to industry, as well as bookbinding and printing. There are 28 factories in the Furniture Group, 27 in the Leather and Textile Products Group and 32 factories in the Packaging and Assembly Group. Each of these groups operates with a substantial degree of line management autonomy supported by professional administrative services at Head Office in Cricklewood in North West London providing financial, commercial and personnel functions. Naturally, in a company which has as its primary objective the care of people, the personnel function is extremely important and for this reason we have located in the field six Area Personnel Managers covering Scotland, the North East, Yorkshire and Humberside, the North West, Wales, and the South, who provide a personnel service to the Factory Managers and employees in their areas.

Work in Remploy provides as near-normal industrial conditions as possible. The conditions of employment include four weeks' holiday, a generous sick pay scheme and assistance with fares to work. The company hopes shortly to introduce a pension scheme which in some respects will be in advance of the State Scheme which came into force in April, 1978. There is a standard 40-hour week for an agreed basic wage, which at the moment is £42.79 in the provinces and £49.38 in the London area. These basic rates apply throughout the company but have built-on to them rates appropriate to the industry in which particular factories operate, and various other plus rates reflecting the nature of the work undertaken. There are also various incentive schemes operating in all our factories. Rates of pay are negotiated with ten trade unions which employees are encouraged to join. Of the ten trade unions, eight form a consortium of unions representing shop floor workers and negotiate with the company as a body. The other two unions are staff unions which negotiate individually.

The company places great emphasis on the enlightened development of its industrial relations policies and it is mandatory that Factory Managers should hold meetings of their Joint Consultative Committees once a month. The Joint Consultative Committees consist of the Factory Manager, Foreman or Senior Chargehand, a staff representative and either one or two disabled employees from each main section of the factory. The function of the Joint Consultative Committees is to provide machinery for consultation between management, staff and employees on matters affecting production, factory conditions, discipline, welfare and holiday arrangements.

The primary objective of these bodies is to keep staff and employees fully informed of matters affecting their work and to enlist their co-operation in regard to problems affecting the smooth running of the factory. A local general practitioner is attached to each factory to provide medical advice to the Factory Manager and to the disabled employees. Factory Doctors are appointed by the company's Principal Medical Officer who is responsible for advising the Board on medical aspects on the employment of disabled people.

The company is looking forward to its future with enthusiasm and optimism, qualified by the overriding economic problems of the country which affect Remploy as much as any other diversified manufacturing organisation. The company's success must be measured primarily by the number of disabled people it is able to employ and in this respect the plans are to employ 8,350 in 1978/79, rising to 8,550 in 1979/80, 8,750 by 1980/81 and 8,900 by 1981/82. Our building programme in the next three years, involving the building of new factories and the replacement of existing factories by new ones, should provide employment for an additional 395 disabled people.

A question often asked about Remploy is whether its objective is social or economic, implying a conflict of aims. We do not see this potential dichotomy as a conflict. Our recently retired Managing Director very well summarised our philosophy when he said: "We do not consider that there need be any conflict between social service considerations in the running of Sheltered Employment and commercial ones. We believe that Sheltered Employment's Role should primarily be that of a social service. We believe that Sheltered Employment should provide work for Severely Disabled People which is at least as satisfactory to the individual employee as is work in open industry. We nevertheless consider that the workcarried out in Sheltered Employment conditions should be done with commercial considerations in mind because cost matters here (as in other human occupations and projects) and needs to be kept down by the achievement of the maximum of sales which can reasonably be made. In this way there can be maximum efficiency without sight being lost of the primary objective, i.e. that it is a social service."

During the 33 years of its existence Remploy has provided employment for more than 40,000 disabled workers. We are proud of this record and feel confident that this immensely significant social work will continue to expand in the years to come.

I would be very happy to endeavour to answer any questions which you may have.

REMPLOY - TEN YEAR STATISTICS

Year	Sales	Disabled Employees Wages	No. of Factories	Average Number Employed	No. Returned to Open Industry
	£	£			
1968	8,064,000	3,750,000	87	7,017	173
1969	8,788,000	4,211,000	87	7,352	227
1970	9,339,000	4,590,000	87	7,448	199
1971	11,266,000	5,247,000	87	7,567	129
1972	13,059,000	5,951,000	86	7,559	84
1973	14,103,000	6,772,000	86	7,960	159
1974	16,013,000	7,803,000	86	7,990	326
1975	20,100,000	9,985,000	87	8,190	236
1976	22,249,000	13,803,000	87	8,370	76
1977	24,923,000	14,804,000	87	8,138	64

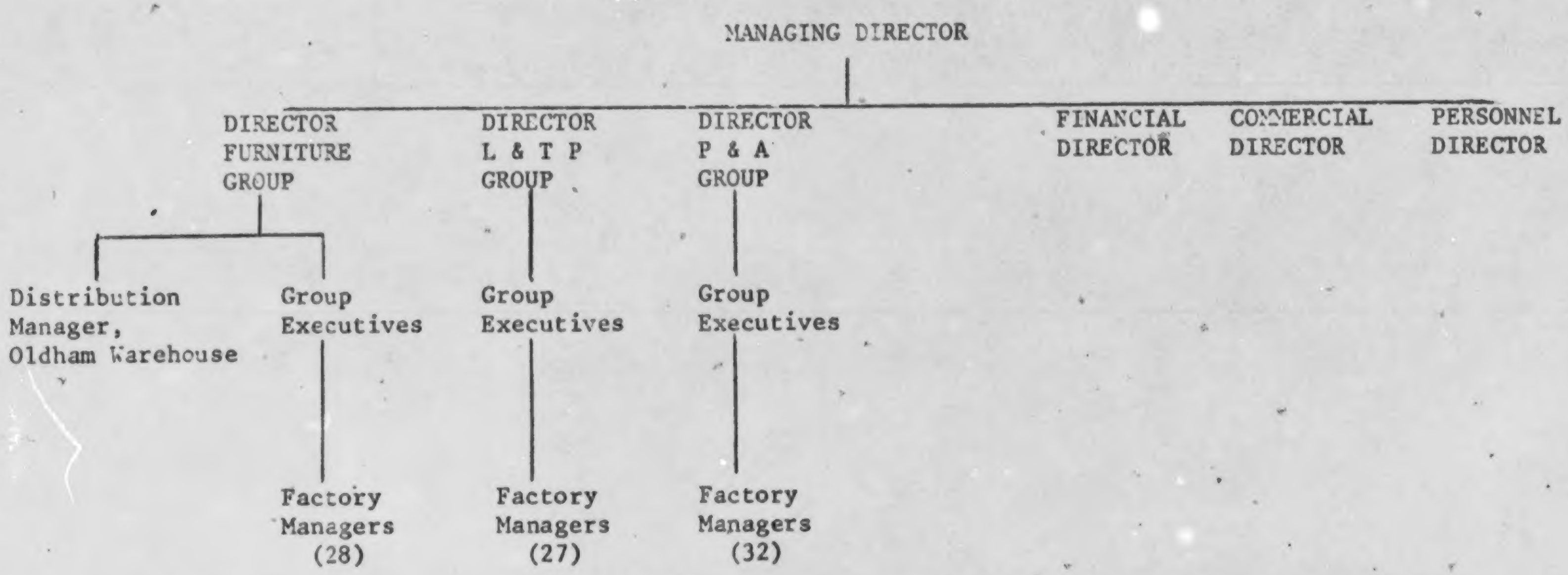
APPENDIX II

TYPES OF DISABILITIES OF REMPLOY'S DISABLED EMPLOYEES

Types	Nos.	%
Amputation	255	3.2
Arthritis and Theumatism	271	3.4
Diseases of the Digestive System	128	1.6
Diseases of the Genito-Urinary System	64	.8
Diseases of the Heart or Circulatory System	614	7.7
Diseases of the Lungs (except Tuberculosis)	550	6.9
Diseases of the Skin	40	.5
Ear Defects	303	3.8
Eye Defects	143	1.8
Injuries of the Head, Face, Neck, Thorax, Abdomen, Pelvis and Trunk	159	2.0
Injuries and Diseases (except T.B.) of lower limbs	686	8.6
Injuries and Diseases (except T.B.) of Upper limbs	255	3.2
Paraplegia	231	2.9
Injuries and Diseases (except Paraplegia & T.B.) of the spine	558	7.0
Psychoneurosis and other mental illnesses	749	9.4
Epilepsy	815	10.2
Organic Nervous Diseases other than Epilepsy	606	7.6
Mental Sub-normality	861	10.8
Tuberculosis-pulmonary	271	3.4
Tuberculosis- non pulmonary	96	1.2
Other Diseases and Disabilities	319	4.0
	7,972	100.0

APPENDIX III

REMPLOY - ORGANISATION STRUCTURE


MANAGING DIRECTOR
DIRECTOR FURNITURE GROUP
DIRECTOR L & T P GROUP
DIRECTOR P & A GROUP
FINANCIAL DIRECTOR
COMMERCIAL DIRECTOR
PERSONNEL DIRECTOR
Distribution Manager, Oldham Warehouse
Group Executives
Group Executives
Group Executives
Factory Managers (28)
Factory Managers (27)
Factory Managers (32)

DISABILITY IN THE FAMILY.

Dr. Ann S. Raikes.

The Concise Oxford Dictionary defines disability as "a thing, a want that prevents one from doing something". Ability is defined as "having sufficient proven capacity to do something, legal competency, financial competency to meet a demand, cleverness, mental faculty". The word "family" is considered to include members of a household, parents, children, dependants, all descendants of a common lineage, nations. Therefore in thinking of the problems of disability in the family we must consider the disabled person, the disabled family due to a disadvantaged relative, the problems of the professionals in acquiring the capacity and competency to minimise disability and, more widely, the necessity for local and national provisions to allow patient and family to remain integrated in the general community in as fulfilled a role as possible. For far too long any form of disability, especially mental handicap, was a subject that did not receive sufficient honest attention. Pendulums often swing too far too fast and in the new attitude to handicapping conditions common sense must be allowed to prevail in keeping the difficulties in perspective. Too rapid growth of too many services in too fragmentary a fashion can occur before the professional and financial competency levels have been fully assessed and achieved. This rapid growth can result in an excess of involved theory which is not practical for patient, parent or society and in provision of services with half-trained personnel being set up on the basis of "something is better than nothing". In my opinion this is only true if the "something" is self-critical and allowed to grow as expertise and experience becomes greater. We are in danger of developing an almost addictive attitude to jargon and pseudo-science as substitutes for true knowledge which can be expressed simply, and in evolving over-complex technology which can be narrow in concept. This approach fails to understand the needs of the people who really matter - the patients and their family coping with the ordinary but sometimes very difficult task of living. It is salutory for all of us, professionals, parents, patients and society to stop and look critically at our roles, aims and theories. Otherwise we will mis-use our skills and technical abilities and run the risk of creating iatrogenic disease and difficulties by our enthusiastic efforts. This is a professional age but we must not forget to be human.

The greatly increased understanding and knowledge about the infinite causes of disability leads to the realisation that some services can only be provided practically on a regional basis. This may mean the placement of a disabled person many miles away from home and cause difficulties of re-integration during holidays or on completion of education and training. Such problems must be planned for at an early age rather than as an afterthought. In the early years parents must be parents first and therapists second but their close involvment should lessen as the child matures. This does not mean however that parental anxiety lessens as maturation occurs, indeed fears for the future often

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become greater as age can increase problems in both patient and family. The training of disabled people must be as individual and practical as possible since sometimes unrealistic job expectations can lead to disappointment and despair at the end of an arduous and expensive training programme. We must also be careful to remember that education and training are not the whole story and only part of the needs of a person in society, and help and thought must be given to the actual practicalities of living rather than existing.

It is necessary to discuss the wider issues and philosophy of disability if the more detailed problems are to be seen in focus. This paper covers in some depth the task of attempting to provide a comprehensive, co-ordinated service for children with developmental difficulties. The complexity of services can easily not be realised until one takes a specific look at the Departments, both statutory and voluntary, that may be involved with a disabled person. It is essential that each District has a Centre where all services are integrated and where all new staff from any discipline can be fully informed about local facilities. In the United Kingdom the Court Report on Child Health Services contains far-reaching suggestions for the future, some have been accepted, some rejected. What must be recognised and listened to is the call for an integrated child and family-orientated service. The integration of Departments and disciplines at casework level is common sense if resources are to be used efficiently to evolve common treatment programmes using each other's special knowledge in the optimum way and ensuring co-ordinated advice and co-operation with the family and patient. This team work must be genuine and generous so that the patient and family are aware of the understanding and efforts of all concerned. Families need to be part of the team providing support and treatment programmes, understanding the reason for treatment and being able to see the problems in perspective. The rest of the family must not be allowed to suffer because parental expectations are unrealistic. In many cases handicap is the only aspect of the child that receives attention and the personality and normal achievements are ignored or pass unrecognised. Different families have different ideas of the norm and it must be appreciated that what in some families is a minor problem in others may be a very major difficulty. If parents and children are helped from an early stage there is hope that as the child matures the family will be able to go ahead with confidence, allowing their child to reach his or her full potential however limited this may be. The types of disability that have been discussed are by inference those of congenital or very early acquisition and, ofcourse, it would not be possible to think along identical lines for disabilities acquired through trauma or illness at a later stage. However the basic concepts still hold true, it will merely mean a more flexible use of therapy and understanding from all concerned.

Since 1969 we have been working together in our Paediatric Department building up what in modern parlance could be called a District Handicapped Team. Our aim is to provide a comprehensive investigation, diagnostic, assessment and treatment service for children and their families in our catchment area when the former are referred because of suspected developmental deviance. It is vital that one always assesses the whole child and his family, otherwise therapy and support will not be effective. This original assessment must be followed by regular

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reviews of the case and therapy so that help can move with the developmental and family needs. We also believe that ample time must be given by all members of the team to the parents so that they can ask questions and feel that they are being given consistent, sensible answers. We have enlarged as it became obvious that there was a gap in the services we provided, this has allowed gradual integration of team members with maximum understanding and co-ordination of approach.

There is a great interchange of information and role playing, depending on personal relationships between therapists and families. We all accept each others extra expertise in each specialist field but there is generosity in counselling each other without feeling threatened or misused. In this way parents are helped to understand the needs of their child, the reasons for the therapy programmes and to feel secure in the general awareness of all team members of their difficulties. Working with young developmentally disadvantaged children is a great challenge as it is not a question of rehabilitation but habilitation. Children do not appreciate a lacked skill if they have never acquired it in the first place and they have to be motivated to work, in children play, in areas of difficulty. Only if therapy can be presented in this way will the child wish to co-operate and so, by their own efforts, minimise their problems, widen their experience and enrich their interests. The therapy is planned very flexibly on an individual or group basis as seems best for the child and family. As treatment and understanding progresses we include children and parents in small remedial playgroups, subsequently in remedial groups with a high staff/child ratio where the child can separate from the parents. At this time the parents have their own support group which meets where they can discuss their difficulties, share their problems, often band together for social outings, arrange baby sitting services and feel that they are still being supported and can support each other. We try not to forget fathers though it is not so easy to arrange meetings with them due to work committments but we try to have an evening "Father's Meeting" at regular intervals so that they feel they are members of the family and professional team helping the child. The child with a disadvantage is still a child in the first place with all the normal needs of a child and a child with difficulties second. It is our aim to establish a good understanding of the child's needs, strengths and weaknesses and to simplify and make practical the remedial programme. We hope that as soon as possible the child can be accepted in a local community playgroup (we liaise with 152 round the hospital catchment area) or correct special placement be found at the earliest opportunity where there are very special needs. The Hospital serves an area of just over 400,000 people, the centralised Paediatric Department Developmental Centre has just over 300 children referred each year with suspected difficulties. We have in our team, apart from the medical personnel, which includes a Child Psychiatrist, Physiotherapists, an Occupational Therapist (soon we hope to have two Occupational Therapists), a Speech Therapist who works part time in the Hospital with our team and part in the community, a Remedial Teacher, part time, who works specifically with us on children with multiple learning disorders and handicaps, three Paediatric Social Workers with psychiatric training, whenever possible a Senior Educational Psychologist, and a Play Therapist who is very skilled in the therapeutic use of play and in helping motivate children to play in areas of difficulty. The Play Therapist is also responsible for liaising with community playgroups and recruiting voluntary workers on whose help we rely heavily tomaintain our high staff/child ratio in the Assessment and Developmental Remedial Groups.

At any one time we have 20 - 30 voluntary workers helping us, some of them have been giving up their time to us over the last five years, and for whom we organise intensive in-service training programmes, but since most of these helpers also have responsibilities in community group activities, this again means that the dissemination of information and expertise is assisted.

The sentiments expressed in this paper are not new and indeed it is interesting to realise that in the early 1970s Professor Ross of the Engineering Department, Cambridge University, gave a series of lectures on the Resources of Technological Man and in his final lecture this Professor expressed the opinion that "there is a great need for the development of values relating more to group activities and less to individual competitive successes. Everyone needs approval and respect for the development of their personality. Could we not provide that sense of worth by valuing each person for his or her particular attributes, rather than by concentrating on the single academic criterion which we use at present for awarding approval? I would advocate a greater relevance of the curriculum at schools and Universities to the problems of mankind in society. In particular, I would favour a lessening of the demarcation between the various subjects and disciplines and greater emphasis all along the line on the inter-relationships between the various fields of knowledge, the various activities of man, within his community and environment. This is sometimes called the systems approach, I see no limit to its introduction at school in simple terms, even in the early age groups". He therefore expressed exactly the same sentiments that our team is expressing today.

There will always be a shortage of funds and facilities but this is an advantage if it makes us use our resources sensibly. We must put forward integrated plans for minimising the effect of disability in the family so that our claims for funding will be high on the list of priorities and we must ensure that our training programmes keep pace with new knowledge and are multi-disciplinary and practical in outlook and content. We cannot compensate for disability. Society can learn to minimise it by accepting disabled people as full members of the community.

Remember, there is a person behind everyone, there is no reason why that person should not be in front.

DISABILITY IN THE FAMILY.

The Changing Scene.

W. H. LAMING.

ABSTRACT

We tend to think of the family as a cohesive and stable unit spanning the generations and existing within a supportive network of close relatives and friends. But in a modern industrialised society family life is changing. What can we expect of the family in the care of people with a disability and what help, both statutory and voluntary, is needed if the family is to be enabled to fulfil this task ? Not only are we experiencing a big increase in demand for community based services but changes in expectations about the quality of life for people with a disability are also making an impact on the level and style of services required.

The theme of this Conference is disability in the family and I suspect that during the course of the Conference we will hear more about disability than about the family. This would be unimportant if there was a general understanding of the family in a modern industrialised society, of the part the family might or might not be able to play in the care of people with a disability, and of the support and help which the family needs to care for a member who has a handicap. In recent decades there have been in this country significant changes which have affected the family unit and of course, in the incidence of distribution of handicap. There has also been a major shift in opinion about disability so that there is now a demand that handicapped people should be enabled to live as independently as their disability allows and, furthermore, they should be helped to play a full part in the life of the community. So I would like to begin by commenting briefly on some changes in family life which may influence our thinking about the care and support of people with a disability, and then comment on the services which are necessary to support those living in a family and those without a family but living in the community.

A number of factors have resulted in social mobility being a feature of modern day society. Far fewer people live a substantial proportion of their lives in the area of their birth and even those who do seem to leave home more often. Social mobility with all of its benefits can bring in its train social isolation and loneliness. The close network of familial relationships and long standing close friendships are no longer available to many families. Furthermore families are smaller. Getting married and starting a family are no longer as closely related than was the case up to a couple of decades ago. Since the mid-1960's two trends have been observed which are that married couples have waited longer after marriage before having their first child and the numbers of third and later children born have fallen substantially. And marriage is less permanent. Whilst the number of marriages fell between 1971 and 1975 the number of divorces increased sharply. Remarriage is also on the increase but separation, divorce and remarriage seldom occur without a period of trauma resulting in the dislocation of family life.

There have been changes in the longevity of life. Although not all elderly people need the social services the fact is that amongst the group 75+ the incidence of handicap increased greatly with age. The range of disability is very great and this group of people need special help in coming to terms with the loss of mobility, the loss of relations, the loss of independence, the loss of self-confidence and sometimes what they feel to be a loss of dignity and a significant role within a family.

Finally, I would like to mention albeit briefly, what I can best describe as the changing expectation of the quality of life. In times past individuals, families and communities were often engaged in a struggle to achieve survival. Nowadays life is still very hard for some people but more and more people are able to pursue a life style which is rather less to do with survival and more to do with seeking after happiness and self-fulfilment.

I have tried to indicate that although we often think of the family as a cohesive and stable unit, spanning the generations and existing within a supportive network of close relations and friends, in fact for many people the picture is very different. They may not belong to a family unit, they may not feel part of a community and they may have few visitors to their home beyond the insurance man and the local tradespeople. For others the family may exist and may be very caring but we serve neither the person with a disability, the family, nor society if the family unit - or the key member of it - is overburdened to the point of breakdown. So what can be done to support disabled people and their families ? Caring involves us all. It cannot and should not be left to the statutory services, particularly as often the real task is how to alleviate the secondary handicaps of social isolation and loneliness which are often responsible for depression, resentment and despair. Be it as relatives, friends, neighbours, community groups, voluntary organisations or volunteers we all have a part to play. But sometimes neighbours and volunteers feel uncertain about involvement in case they find themselves manoeuvred into a position of responsibility, exploited because of their willingness to help and expected to cope with a task much beyond their abilities. To avoid this and to encourage more good neighbours and voluntary effort we must develop an adequate network of services, which together form the framework which is essential if others are to feel able to play their part effectively and comfortably.

The term disability is used to describe something which may amount to a small impairment to a bodily function to the most severe of handicaps. Perhaps because this is a complex subject many people tend to think in terms of stereotypes - even the widely acknowledged 'Access' sign on public buildings depicts a person in a wheelchair, but in fact the human body is, as we know vulnerable to an astonishing variety of physical and functional disorders and illnesses, few of which necessitate the use of a wheelchair and many of which are not observable to the onlooker - the most notable example being that of profound deafness. Advances in medicine, particularly in preventive medicine, have reduced the number of children born disabled but at the same time these advances have meant that some disabled children now survive where once they would have died, an example is the survival into adolescence of those children born with spina bifida. Greater longevity means a greater proportion of the population with handicaps associated with old age. In addition there is increased disability caused by road accidents and other traumatic experiences. Figures indicate that 2.7% of the adult population suffered a handicap which considerably impaired their daily living. Because of the range of disability and because it is essential that all of the services underpin and support the uniqueness of the individual the first essential to helping the disabled person within the family is that of the development of a truly multi-disciplinary team. It may not be possible to free the person from his handicap but it ought to be possible to alleviate the secondary handicaps which result from disability and which are in many instances more disabling. To concentrate solely on the disability is to deny the whole person and to do a dis-service to both the individual and the family. The difficulties do not stem from the way the services are administered but they depend upon the availability of trained staff and upon the representatives of each discipline understanding and valuing the contribution of others for the benefit of the handicapped person and the family. Unfortunately the pressure on most social services departments are such that a priority rating has to be accorded to all referrals. Although the speed and style of reaction by the personal social services department ought to be dependent upon individual need irrespective of client group, the practice can be very different in that social workers are not yet well equipped to tackle this area of work and people with a disability are often referred directly to an occupational therapist or to a social work assistant.

When we have sufficient social workers and sufficient occupational therapists, properly trained in understanding disability and its social consequences, then departments will be able to play a full part in the multi-disciplinary assessment of handicapped people. It should then be possible to identify key workers at different stages in development, able to play the major role and be responsible for keeping others informed of progress and problems. People with a disability understandably want to return home from hospital as quickly as possible and hospitals want to use their resources for treatment rather than residential care. But discharge from hospital not only needs to be planned on a multi-disciplinary basis but due recognition must be paid to the fact that decisions about discharge can be taken more easily than the making available of essential services.

The fostering of independence is crucially important in helping people with a disability, but often the biggest impediment to greater independence is over-protectiveness and the fear of risk taking. Disability is not synonymous with inability or unwillingness to help one's self, and simply to provide aids to disabled people may add to feelings of inadequacy and dependency. Occupational therapists are very skilled in helping people with a disability and their families see what might be achieved by the handicapped person, and the aids available to facilitate this achievement. There is a danger that the pressure on the statutory services to reduce the risk to people actually works against their best interests. All life involves some degree of risk and many disabled people are only too well aware of the fact that sometimes decisions are taken on their behalf by able-bodied people which restrict their freedom. Disabled people should be given the right to choose and be positively encouraged to make decisions because this is part of the process of achieving independence. Services should be provided on the basis of assessed need and not on demand and although it is often necessary to discriminate in favour of people with a disability it is important that privileges should not be thought unreasonable by non-handicapped people or it produces a negative reaction. An example is the orange badge scheme for car parking.

A person with a significant disability living in the community needs help both within the home and help outside the home. One of the most telling examples of the way in which society has in the past virtually ignored the needs of handicapped people is in the field of housing, yet unsuitable housing is probably the main factor which restricts freedom and increases dependency. In recent years a great deal of attention has been devoted to the development of mobility housing and some degree of choice within the public sector now exists for disabled people and their families. The Chronically Sick and Disabled Persons Act 1971 has done much to focus attention on the needs of disabled people particularly for specially designed or adapted housing, and it is hard for able-bodied people to understand the enormous impact which can be made on the life style of a disabled housewife once she is enabled to have access to all parts of the house, either because of mobility housing or because of adaptation. Those who have seen it happen for some will no doubt want to see it happen for a great deal more.

The level of services available in this country today for people with a disability and their families shows an enormous improvement on the services of a decade ago. Great progress has been made but alongside increased provision has been a dramatic change in attitudes and expectations. This has resulted not only in an increase in demand well above the increase in services but also a change of demand. Let me illustrate both points.

In recent years the potential of the home help service has begun to be recognised. This service does not provide a comparatively cheap domestic worker, on the contrary it provides skilled help on a domiciliary basis. The help may not always be in the home, it may include essential shopping, the making of appointments, or the arrangements of contacts for the disabled person, and those who are familiar with the new breed of home help and the intensive care which can be provided by a family help will know that sometimes these staff, who are both male and female, are able to keep together a family unit which is at the point of breakdown. It is not uncommon for a home help or family help to operate as a substitute for a caring relative. The service has expanded greatly in recent years but unfortunately the referral rate to this service in some parts of the country has increased at a rate considerably higher than the growth of resources and as a result fewer hours are being provided to each household. A similar increase in demand is experienced with the meals on wheels service which is of growing importance, particularly for people with a disability associated with old age. Many such people are housebound and live alone and the importance of the social contact is equal to that of the nutritional value of the meal. An increasing number of elderly disabled people need the availability of a meals service seven days a week but unfortunately in some areas the meals on wheels service exists on only two or three days a week, and the provision of a laundry service for fouled linen is available in only a few areas.

The second point about changing expectations can be illustrated simply by the fact that sexual fulfilment for people with a disability was hardly discussed ten years ago, now it is generally accepted and residential provision must respect the need for privacy.

The concept of shared caring is one which needs to be extended. The statutory and voluntary services cannot replace the family but they can support and relieve the family and thereby share in the caring process. Whether it be in the provision of day care or of the planned night sitter service, or the planned intermittent residential care, families can be helped greatly if they feel supported by a network of services and can rely upon relief at certain times. The use of residential provision in a way which allows a disabled person's family to have the occasional break, or even a planned admission of one week in three, is an area of work which needs to be expanded.

Day care or help outside the house cannot cope with increased demands and changing expectations. Some of the younger handicapped people require more than a day centre, they need to be provided with a work centre which offers them a rehabilitative experience toward full time employment, or for those who cannot sustain full time employment an opportunity to make a limited contribution toward a national economy.

Finally, I would like to emphasise the importance of social contact for disabled people. Aids to living of various sorts may increase independence and help disabled people in numerous ways, but human contact on a regular basis improves morale and enhances a sense of well being. Visiting the housebound needs to be reliable and frequent, never patronising, and always with a courtesy which we would hope that others will accord to ourselves. The scope for voluntary effort is great but volunteers need to be carefully selected, to be well informed and well supported, and this may include financial support to cover out of pocket expenses. All of this demands staff skilled in this area of work with sufficient time to do it well. Community care is an oft used expression but it is rarely defined in practical terms. If it depends upon a non-existent family, or the overburdening of a caring relative or neighbour, or the occasional contact with one of the statutory or voluntary services, then in reality it may seem to be a worthless concept to a person with a disability. To provide the kind of care which takes into account both increasing numbers and changing expectations will require a huge expansion of services, both voluntary and statutory. Community care is sometimes thought to be relatively cheap. Of course it can be if it hardly exists. If the full range of services are to be available to disabled people and their families then community care is not a cheap option but the preferred option for many people with a disability, because it offers an improved life style, greater independence and a better hope for fulfilment. In this society and I suspect many others, in recent years we have come a long way in achieving an improved level of services, but we still have an enormous task ahead of us before we can claim that a comprehensive community based service is a reality for those who have disability in the family.

ACCESS TO HIGHER EDUCATION IS BY ATTITUDES RATHER THAN ARCHITECTURE

Judith Crosby* & David Spooner**

1. Attitudes versus architectural accessibility, which is it that really helps or hinders access into higher education.
2. How accessibility is really only part of a much larger question.
3. How attitudes are reflected in the following very important questions which are fundamental to the discussion of disabled in higher education:
    (a) What is education for?
    (b) What type of disabled person is accepted?
    (c) Does accessibility actually change people's awareness to the problems of the disabled?
    (d) What next after the course has finished?

The traditional argument used for excluding disabled people from higher education is that if academic buildings and accommodation are not accessible then they are justified in turning down a disabled person's application. This therefore poses the suggestion that architectural design is the main obstacle encountered by disabled people entering higher education. Is this in fact the case?

At Sussex University attempts have been made to alleviate some of these accessibility problems. For example, their first major step was the building of Kulukundis House. This is a residence specially designed for the use of disabled students. The University has also done much to improve accessibility internally (ramps, lifts etc.). This is made easier by the relatively low buildings and its natural geography. However problems still exist. Some of the routes that disabled students have to take are long and complicated so that steps can be avoided. This means that more often than not the disabled person is negotiating territory outside the normally frequented routes of access so that if a push is required for a wheelchair it may be difficult to find people or people have to go a long way out of their way to be of any assistance. It is therefore necessary to allow extra time in getting to and from lectures, tutorials, etc.

Difficulties also arise at the library. Again access is not the same as that used by other students. Library shelves, carpeting and other obstacles hinder the full use of the library facilities although this can in some measure be overcome by the use of the Readers' Advisory Desk. Here the assistants will look out the books for the disabled person but a time factor does come into play here too. With the shortage of books it is easy to become disadvantaged in relation to other students whose main object is to get to the book shelves first.

It is also wrong to assume though that the problems that disabled people face are purely physical and can be overcome just by architectural alterations. Architecture as an issue clouds over a lot of other more major problems inherent within the whole structure of our educational system. It is therefore important to stress that although Sussex has been able to provide facilities for the disabled this should not be the major reason for coming to Sussex. Choice of course should always be the first priority. This would mean that if a more suitable course is offered at another university then pressure should be brought to bear on them to offer the same opportunities as does Sussex. This would then prevent Sussex from becoming a ghetto for disabled students which some fear that it will become.

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So what are the educational problems that disabled people have to face? First we have to consider what is required from the disabled student in order to gain admittance to the University. The admissions procedure can roughly be divided into three distinct criteria:-

1. Academic Qualifications. As with all students the disabled have to be equipped with the necessary 'O' and 'A' level qualifications. This is in effect the most difficult barrier of all. Good 'O' and 'A' level grades can be more important than for the non-disabled - in order to 'prove' their academic capability 'in spite of' their disabilities. The number of institutions whereby disabled people are given the necessary provisions in order to pass exams are extremely limited. Often the age of people at the time of disablement can be of crucial importance. For example, if one is disabled after passing the 11+ exam (or its equivalent) the education authorities can be obliged to provide secondary education of a sufficient standard to ensure that an attempt at 'O' levels can be made. Thus this has serious implications for those disabled from birth who do not have such opportunities open to them. Also, the manner in which one is assessed at 'O' and 'A' level remains the conventional sit-down examination. The physical and psychological requirements for such a gruelling task are obviously exacting and may provide serious obstacles to most disabled persons who in other respects are perfectly capable of high academic intellectual standards.

2. Counselling. Having been approved on conventional academic grounds the university then attempts to find out whether or not the disabled person would be able to cope with all the ancillary problems faced by students. This obviously includes possible special medical needs, psychological problems etc... concerned with living at the university as well as the ability to interact with other students and tutors, i.e. to be able to take part in all the activities surrounding University life outside of the academic work itself. Also considered at this stage is our third criterion - the ability of students to cope with the examination procedures.

3. Examination Procedures. If it is thought that the disabled person would be unable to cope with the Final Exam procedure he or she would be rejected. The examination procedure at Sussex is notoriously complex, consisting of a mixture of sit-down exams, extended essays, dissertations, "take away" exams, "seen" exams and other assorted hybrids. Each form requires a considerable number of physical and psychological qualities. It is interesting to note that no other students are asked to show ability to take examinations etc. when the evidence suggests that the major problems concerning examinations are common to all students, e.g. psychological obstacles. It is here that one must consider whether or not it is right that disabled students are rejected from the university on grounds of examination potential irrespective of the education gained (but not

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necessarily measured) over the three or four years teaching which has an inherent value. It is important, however, that disabled students are not made 'exempt' from exams, but rather that the entire exam process be re-evaluated and changed.

Having crossed the many obstacles facing entrance to University, what problems do disabled students face, apart from the obvious architectural ones?

These are mainly those of attitudes and lack of experience held by members of faculty and other students. The majority of tutors and students have never experienced working with or living with disabled people. Their reactions may be said to be of one or two general descriptions. First, there are those who unwittingly treat the student as a 'disabled object' to be politely tolerated and excuses made for. For them, the work undertaken by the student is regarded as relatively unimportant, the 'being at university' degenerates to be the mere presence at the institution. Thus, during tutorials etc. little constructive criticism is made, little help offered, and the barest appraisal of work is given for fear of 'hurting feelings' etc. Secondly, there are those who attempt to treat disabled students as 'normal' students. This causes just as many problems because disablement does present difficulties in learning at the university - writing speed, library facilities, possible speech impediments, etc. which cannot be overlooked. What is needed is for everyone concerned to begin to fully understand what it means to be a disabled student in order to liberate the disabled students from the patronization or academic rejection which can be unwittingly imposed.

In this context the 'Chronically Sick and Disabled Persons Act' (1970) seems wholly inadequate:

> "Any person undertaking the provision of a building for (educational) purposes shall, in the means of access both to and within the building, and in the parking facilities and sanitary conveniences to be available (if any), make provision, in so far as it is in the circumstances both practicable and reasonable, for the needs of persons using the building who are disabled."

Although it is clear that such changes in policy or attitude towards accessibility have considerable importance, it is of little value unless they reflect a genuine change in access to education itself. Indeed the opening up of educational buildings in effect only highlights the inadequacies of the nature of the education offered within.

Questions of "what is education for?" are constantly raised - but very rarely so clearly stated as the question of disabled people experiencing education. For example, what opportunities are open to disabled graduates? What vocational role should education play for disabled people? After three years of relative independence and growth of horizons, what can be done to prevent the necessity of returning home and retreating back into 'disability'?

If the relevant changes are to be made in education, they will have to be made across the board as we recognise that no 'special case' should be made for disabled students. By stating that disabled students have the right to equality of access to all aspects of further and higher education - this leads to the conclusion that all people deserve open and genuine access to the facilities available.

The importance, therefore, of attempting the fullest integration of disabled students into further and higher education and the integration of further and higher education into the lives of disabled students is that it is not restricted to those in a specialised category but so that it has repercussions for all involved in education.

The whole question obviously needs urgent research - research (as far as we know) which has not even begun. We therefore intend to set up some form of national organisation to investigate the problems of educational accessibility beyond the architectural restrictions.

THE RUTLAND STREET PROJECT

Séamas Holland

Abstract

The aim of the Rutland Street project was to develop strategies to prevent school failure among disadvantaged children.

This paper gives some background information and a brief description of the project area. It describes the main features of the educational programme developed for the project and some of the strategies used to promote the more active involvement of disadvantaged parents in the educational process.

It describes the evaluation of the project in terms of the progress of the experimental group during the life of the project and in terms of a comparison between the performance of the group on standardised tests of ability and attainment with that of two control groups.

Some tentative conclusions are put forward based on the experience of the project.

THE RUTLAND STREET PROJECT

Séamas Holland

1. Introduction:

The Rutland Street project began in September 1969 when 90 three-year old children were admitted to a purpose-built preschool centre. These children will be referred to in this paper as the experimental group. The experimental period of the project ended in June 1974. The funding was provided in roughly equal proportions by the Irish Department of Education and the Bernard Van Leer Foundation, the Hague.

It may be useful to note at the outset that the children were not selected for the project on the basis of any known physical or mental disability. In fact the entire three year old population of the project area were admitted to the preschool centre in 1969. (Access to public primary schools in Ireland is available to all children in the state from the age of four.)

The Rutland Street area was chosen because of the extremely high rate of scholastic failure among those attending the local primary school. It was assumed that the project children were destined, without intervention, to share the inability of their older siblings to cope with the demands of the formal educational system. The aim of the project was to develop strategies to counteract the scholastic failure which would confidently have been predicted for these children. If the strategies proved successful measures would be taken to implement them in similar areas throughout the Irish school system.

The project area is characterised by the kinds of social and economic phenomena normally associated with people living in down-town parts of large cities. These include unemployment, ill-health, low income, an inability to match resources to needs, overcrowding, violence, etc. Society in general and educationists in particular do not expect children from such environments to show much educational promise. This expectation is frequently fulfilled.

2. Premises and Staffing:

The project was based in a new building which has six learning areas grouped round a larger central area. Each learning area catered for a group of fifteen children and was staffed by a teacher and one other adult. The children attended either a morning session from 9.30 to 12.00 or an afternoon session from 1.00 to 3.30. Thus the school had a staff of six teachers and six assistants. Three social workers were appointed to devise a programme of parent involvement. The author of this paper was seconded by the Department of Education to undertake the overall direction of the project. Evaluation was in the hands of an Educational Research Institute whose director was a part-time member of the project staff.

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At the end of two years in the preschool centre the children transferred to a junior school, also specially built for the project. This school was part of the normal school system and so the children followed the normal curriculum. They attended from 9.30 to 2.30 each day. A teacher was assigned to each group of twenty-five children but the services of a full-time assistant were not available. The majority of the experimental group spent the remaining three years of the project in this school.

3. Intervention Strategies:

Two main intervention strategies were used (i) the development and implementation of a curriculum based on Piagetian theories of child development and (ii) continuous, though largely unstructured, attempts to increase the active participation of parents in the education process.

3.1. The Curriculum: This was planned under three main headings

3.1.1 Language Development: Language, as a means of structuring experience and of storing information about the environment, is seen as an essential tool of scholastic progress. Thus an important aim of the school programme was to extend the children's vocabulary and to increase the range of linguistic structures available to them. Teaching strategies were planned with this aim in mind. These included the strategies usually associated with the nursery classroom such as stories, rhymes, news and conversation based on a current activity, as well as lessons focusing on a specific linguistic structure.

3.1.2 Cognitive Development: It is accepted that children need to develop a range of skills to structure the wide variety of sensory experiences which are available from the environment. Knowledge of the properties and characteristics of common objects is seen as an essential basis for the development of relevant cognitive skills such as matching, ordering, classification, making inferences on the basis of partial information, interpreting codes and so on. Thus the children were exposed to a wide range of concrete materials, and tasks were devised which provided opportunities for the practice of these skills at increasing levels of difficulty. Attention was also given to the development of the children's ability to sequence objects and events in space and time.

3.1.3 Social and Personal Development: The thinking of young children is described as egocentric. This may be especially true of young disadvantaged children whose early experience of adult behaviour may have induced feelings of mistrust. Not only are such feelings calculated to affect their social behaviour but they are also likely to affect their logical behaviour in that they may be unable to predict how an adult will behave in any given situation. Thus every effort was made to create relationships of warmth and trust between adults and children at the centre. Children were encouraged to share, to take turns, to use language rather than physical means to attain their ends. The development of concentration and task-persistence was also encouraged. Opportunities were provided for the children to engage in socio-dramatic play, a form of activity with which disadvantaged children are supposed to experience difficulty. The general aim of all of these activities was to accelerate the children's progress towards more mature and rational forms of social behaviour.

3.2. Parent Participation: Direct involvement of parents in the formal educational process is not a notable feature of the Irish school system. There is general acceptance by teachers of the crucial importance of parental support for the aims of the school but little organised effort on the part of teachers to influence parental attitudes and teaching styles. Evidence available from intervention projects in America suggested that action which was confined to the school was unlikely to produce lasting effects on the children's intellectual behaviour. Thus the second main aim of the Rutland Street project was to develop the ability of the parents to take an active part in their children's education.

A teacher visited the home of each child prior to his admission to the project. The parents were assured that they would be welcome to visit the school and to participate in classroom activities. Most of the parents accepted this invitation and relationships between them and the teachers were characterised by complete openness and an acceptance of their joint responsibility for the educational progress of the children. Frequent meetings were held at which the purpose of the classroom activities was discussed. On average about half the parents attended these meetings but, while some were present on all occasions, a small minority rarely came. Not surprisingly, at least in the context of a disadvantaged community, mothers greatly outnumbered fathers, although unaccompanied fathers did on occasion attend.

Three social workers had been assigned to the staff of the project with the specific objective of strengthening the links between home and school. A detailed description of the deployment of these social workers would be beyond the scope of this paper. In general they were unable to accept the strong educational orientation of the project and they saw their role as the provision of an intensive casework service to a limited number of severely disadvantaged families. This was undoubtedly a necessary and valuable service but it soon appeared that it prevented the social workers from filling the broader educational role which had been envisaged for them. Various efforts were made to specify tasks which would be more in accordance with the overall aims of the project but these proved unsatisfactory from the point of view of the social workers who eventually resigned from the project.

4. Evaluation.

4.1. Pattern of Intelligence Scores.

The Stanford-Binet intelligence test was used throughout the project as a measure of general mental ability. The test has a mean of 100 with a standard deviation of 15. It was given to the children of the experimental group in November of each year from 1969 to 1974.

The accompanying table shows the mean intelligence of the group as measured by the test on each of these occasions.

Year	1969	1970	1971	1972	1973	1974
Age	3	4	5	6	7	8
Mean Score	93	96	99	95	96	91

The mean intelligence of the group had reached the average for the general population by the end of their period in the preschool centre. Thereafter, it declined to slightly less than its original level. It is interesting to note that this pattern of initial gain followed by progressive decline corresponds closely to that reported for many American intervention programmes. It is also interesting to note that the drop in the children's measured intelligence began to take place after they had been exposed to the more formal curriculum of the primary school. Viewed in isolation the result is disappointing, but, as will be shown later, there are grounds for assuming that their experiences in the project conferred some benefit on the children's intellectual functioning.

4.2. Comparison between Groups

Two control groups of children were used as a basis of comparison with the experimental group.

One of these - the local control group - consisted of sixty children who were eight years old when the project started and who had lived since birth in the Rutland Street area.

The other - an outside control group - consisted of sixty eight-year old children chosen to reflect the average performance of children attending schools in the Dublin area.

In addition to the intelligence test, two tests of reading attainment were given to all three groups. The accompanying table gives the mean scores for the groups on the three tests.

	Experimental Group 85 children	Local Control Group 60 children	Outside Control Group 60 children
Year	1974	1969	1969
Age	8	8	8
I.Q.	91	85	105
Irish Reading	87	83	108
English Reading	80	80	104

4.3. Comment on Results

The mean intelligence of the experimental group was superior to that of the local control group. It seems reasonable to assume that the difference was due, to some extent at least, to the effects of the special programme provided in the project.

Perhaps the most significant aspect of the results is the wide gap in intelligence and attainment between the two disadvantaged groups and the outside control group who, it may be repeated, were carefully selected to represent the average performance of Dublin children. This points strongly to the inhibiting effects of a disadvantaged environment on intellectual development.

The second striking feature of the results is the failure of the experimental group to show any advantage in English reading attainment over the local control group who had not received any special educational treatment.

4.4. Variations in Performance within Experimental Group

In an attempt to find some explanation for this latter phenomenon, the scores of the experimental group were subjected to further analysis. It was discovered that the group could be divided into three sub-groups (i) 23 children who continued to live in the Rutland Street area and who transferred from the junior school to the local primary school, (ii) 39 children whose parents had moved to the suburbs and who were attending a school near their new homes, and (iii) 23 children who continued to live in Rutland Street and who transferred from the junior school to a neighbouring school.

The accompanying table shows the test scores for these three sub-groups.

Experimental Group 1974 (8 years)

	(i) Living in area attending local school	(ii) Living in suburbs attending outside school	(iii) Living in area attending neighbouring school
No.	23	39	23
I.Q.	85.3	91.3	95.9
Irish Reading	82.5	87.6	90.8
English Reading	69.4	81.2	85.6

A comparison of the scores of sub-groups (i) and (iii) suggests that the quality of their school experience was the main factor which influenced the performance of the children. It may be pointed out, however, that the parents of sub-group (iii) actively chose an alternative school for their children while the parents of sub-group (i) elected to allow their children to transfer to the local school. This points to the operation of certain processes in the homes of one sub-group and to their relative absence in the homes of the other. Whatever these processes may be, they seem to have had an effect on the cognitive development of the children prior to their entry to school as the accompanying table indicates.

Experimental Group 1969 (3 years)

	(i)	(ii)	(iii)
No.	23	39	23
I.Q.	89.8	92.3	97.5

This interesting finding relieves the school of some, at least, of the responsibility for the very poor scholastic performance of the children in sub-group (i) although it emphasises the comparative weakness of the school as a compensatory agency.

5. Conclusion

It is obvious that the Rutland Street project did not achieve its aim of developing strategies which would counteract school failure. It has, however, provided clear evidence in a strictly Irish context of the complex and intractable nature of the problem. It has caused many teachers and educational administrators to examine traditional assumptions about the general effectiveness of our educational institutions. Moreover the efficacy of simple administrative measures to solve deepseated social and educational problems is being questioned. For example, a reduction in class size has long been regarded as a panacea for all educational ills. An examination of the project's results lends little support to this view.

Two conclusions may be drawn:

(i) an effective strategy is urgently needed to enhance the learning opportunities available to children of severely disadvantaged children during the first three years of life and

(ii) the learning styles of disadvantaged children and the way cognitive development takes place in a disadvantaged environment are still

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(ii) cont.

poorly understood. The art of teaching has not yet been able to devise instructional techniques which would cater for the severe learning difficulties of these children. These issues have been taken up in further studies arising out of the Rutland Street project.

Various strategies to involve parents, including a home-teaching approach, have been tried with parents of subsequent groups of children in the preschool centre. The reaction of the parents continues to be very positive and one assumes that their behaviour towards their children has been modified to some extent by their contact with the staff of the centre. What matters, of course, is not what parents say they do but what they actually do with their children and techniques of measuring such behavioural changes are still at a rudimentary stage.

At the level of the classroom, the performance of disadvantaged children in seven schools in Dublin has been carefully evaluated over the past four years using a criterion-referenced approach. Preliminary results suggest that basic scholastic skills can be acquired by less talented children if the learning task is analysed and presented in small enough steps and if the child's progress is carefully monitored. A description of this project would, however, require a separate paper.

PSYCHOLOGICAL RESPONSE TO ILLNESS AND ITS EFFECTS ON THE OUTCOME OF OCCUPATIONAL REHABILITATION.

Charles Burdett * and Christopher Olsen. +

ABSTRACT

This investigation is to discover which aspects of a chronically disabled person's response to his disability are relevant to his occupational rehabilitation. The following factors are suggested to be of importance when considering a patient's rehabilitation:-

a) The perceived control of the illness.
b) The information the patient has regarding his illness and his rehabilitation course.
c) The interpretation of the information concerning the illness and its course.
d) The patient's level of anxiety in rehabilitation may be independent of his instrumental response.
e) Family empathy may be directly related to successful rehabilitation.

The following factors will be relevant to predicting occupational rehabilitation:-

a) Factors related to response to illness and meaning of illness.
b) Depressive symptomatology.
c) Perceived control of illness.
d) **General** measures of perceived control.
e) Reported levels of anxiety.
f) The correlation between patient's results and the results judged by the family.

METHOD

It is proposed that a within subject occupational study be carried out and that the clinical measures will be compared to occupational outcome.

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PSYCHOLOGICAL RESPONSE TO ILLNESS AND ITS EFFECTS ON THE OUTCOME OF OCCUPATIONAL REHABILITATION.

[*]Charles Burdett and [+]Christopher Olsen.

The purpose of this investigation is to discover which aspects of a chronically sick or handicapped person's attitude to his disability are relevant to his occupational rehabilitation. It is also proposed to investigate whether his family's attitudes to the disability are relevant in predicting occupational rehabilitation.

The need for such an investigation has grown out of the realisation in recent years that a more effective relationship needed to be established between Hospitals and Employment Rehabilitation Centres. The Clinical Psychologist should be able to provide a more effective assessment service within the hospital to define which patients would most benefit from being referred to Re-employment Services, and should also be able to give more accurate information about prospective trainees on a rehabilitation programme. The Occupational Psychologist would then be able to design programmes suited to a patient's individual needs. This need for greater interaction between Clinical and Occupational Psychologists has been highlighted by Trethowan (48). Information about psychological correlates to vocational services will improve the referral method and help in the setting up of training programmes aimed at rehabilitating the patient to his maximum level. A further benefit is that it will also enable the Clinical Psychologist to design more effective pre-referral programmes aimed at bringing the patient up to a level where he is suitable for vocational retraining.

Many writers have considered the patient's emotional response to his illness. The most common responses noted are depression and denial. There has been a tendency to unite these two concepts into a continuum, with depression representing a high level of arousal and denial a low level. The work on depression is unfortunately marred by a lack of definition. Wright (53) conceives depressive reaction to illness to be a mourning reaction: implicit in this conceptualisation is that the sick or handicapped person has a realisation of loss. This reaction is seen to be necessary to develop new coping mechanisms. Cleghorn and Curtis (9) however, describe the depressive reaction to illness as having the following components: reduced spontaneous movement and verbalisation; helplessness and self-deprecation; insomnia; anorexia; weight loss and constipation; reduced sexual drive; incapacity for physical or mental effort; increased frequency of somatic complaint. Studies of suicides in various groups of chronically sick or physically disabled patients have indicated higher levels of self-destructive behaviour. Farberow et al (13) noted such trends in diabetics and in patients with cardiac and pulmonary diseases. Hopkins (22) noted higher suicide rates in groups with spinal cord injuries, orthopeadic disorders and amongst amputees and Abram (1) noted a high incidence of suicide in dialysis patients, although it was higher amongst patients on unit based dialysis.

Depressive reactions have been noted to exacerbate the physical condition of the patient, and Mason (32) cites various authors to show that depressive symptomatology is associated with the least favourable disease course in cardiac disease, multiple sclerosis, tuberculosis, rheumatoid arthritis, diabetes and malignancy. It would seem that

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depressive reaction has an important role to play in both the physical condition of the patient and his adaptation to illness. McDaniel (34) states however that the idea of a depressive reaction being the logical consequence of a realistic realisation of loss is a "misrepresentation which would lull clinicians into ignoring the response.". He suggests that the model presented by Moos and Solomon (36) would offer a more effective view in which further investigation would be prompted. Moos and Solomon (36) suggest that the failure of effective defence measures against the threat of disability, the generation of anxiety and depression, and increased functional incapacity are inter-related. This suggests that depression would decrease adjustment to illness if allowed to progress unabated. Verwoerdt and Dovenmuchle (49) have suggested that depression in illness is associated with low self-esteem and high anxiety; that the physical severity of the illness is not related to the development and severity of the depression; and that hospital admission could generate depression as a result of situational stress and isolation.

The situation regarding depression in illness is still confusing due to a lack of definition of the term "depression". It has been pointed out (2) that depression has been used as a term for a normal mood state (e.g. grief), for a symptom synonomous with sadness, and for a syndrome characterised by psychomotor retardation or agitation, dejection, hopelessness, self-denegration, suicidal preoccupation, insomnia, anorexia, and loss of libido. All these factors appear to have been observed in sick people and defined as depression in its various forms, so that although the definition is unclear, the symptoms seem to have had an effect on rehabilitation. Two major factors seem to be important; first, the onset of the illness regardless of its severity, and second, the change of external environment that a sick person may be subjected to in his treatment.

The concept of denial is frequently mentioned and this also has a range of meanings. Weinstein and Kahn (52) defined five expressions of denial. These are:- complete denial that the illness is present; denial of the major illness of incapacities but a stressing of the less threatening aspects of illness; minimisation of the illness or attributing it to a benign cause; projection of illness; temporal displacement of illness with an admission of past difficulties but not present ones. Various authors have described patients as exhibiting denial in a variety of illnesses although the exact nature of the response is unclear. There also seems to be some discrepancy over whether it is an adaptive or maladaptive response. Authors (11, 20, 50, 19) have all produced evidence to suggest that denial is a protecting mechanism against overwhelming anxiety during certain stages of illness. However, others have pointed out that denial can result in a tendency not to comply with medical advice (10); to a delay in seeking help which may prove fatal (18); and to a poor rehabilitation prognosis (34, 6).

Friedlander (15) has tried to explain denial responses in patients suffering from hemiplegia as a perceptual dysfunction. Support for a perceptual defect view has been provided by Sullivan (45) who demonstrated that denial can be produced in a normal population by distorting perceptual feedback. It has also been shown that knowledge of illness can influence both the patients' response to treatment and their rehabilitation potential (46, 28, 42). This will be dealt with later.

Anxiety reactions have been observed frequently in people with chronic illness and physical handicaps. It has been reported as being the commonest psychological response of patients in a coronary care unit

(14). Katz (25)highlights the problems of an individual patient undergoing haemodialysis. It would seem that each illness or handicap has its own individual problems which can act as sources of stress which may or may not be found in other disorders, but that it is also stressful to suffer from any illness.

A useful paradigm to employ in understanding a patient's response to illness is that of Seligman (43). Seligman's basic premise is that "when an animal or person is faced with an outcome that is independent of his responses he learns that the outcome is independent of his responses". He points out that behaviourally, this will tend to diminish the initiation of responding in order to control the outcome; cognitively, it will produce a belief in the inefficiency of responding, and difficulty at learning that responding succeeds; and emotionally, when the outcome is traumatic, it will produce heightened anxiety, followed by depression. His theory has three basic components; information about the contingency, cognitive representation of the contingency (learning, expectation, perception, belief); and behaviour. Within this theory, he raises the problems of control over the environment and the predictability of future events. In the statement of theory he postulates that a person can learn to perceive that his responses will not result in any predictable outcome and that he does not have control of his environment. He also considers a situation in which the person cannot control noxious stimulation but can predict its occurence. He can thus take action to minimise its effects and will also know when he can act unimpeded by noxious stimulation. Much of the research into learned helplessness has followed a model in which an animal or person is placed in a situation in which he is subjected to noxious stimulation over which he has no control or over which he perceives that he has no control; observations are then made of his behaviour. His responses are then compared with the responses of a person in a similar situation who can either predict the occurence of the noxious stimulation, who believes that he has control over the noxious stimulation, or who has actual control over the noxious stimulation. It has been demonstrated that those people who have no actual or perceived control over noxious stimulation are more likely to demonstrate responses analogous with anxiety and depression. However Seligman does point out that responses are subject to individual differences.

A person who develops an illness or who suffers an incapacitating trauma is subject to a traumatic change in his personal environment. His response to this change will be dependent on a number of variables. These include the nature of the disease process; the perceived control the patient has over his environment; predictions the patient makes about both his environment and disease course; information available to the patient; and the interpretation of given information. The effect of these variables will depend on whether the disease can be treated quickly and effectively, and whether it can be treated at all. If the disorder is chronic, the patient's response to his disorder will depend on whether the disorder is stable, progressive or subject to random attacks and remissions. However, it is possible to make some suggestions concerning a patient's response to illness. Any sick person suffers a change of environment whether it is internal or external. This change results in some loss of control which in turn results in a patient suffering anxiety. If the disorder is not immediately curable, the patient will be placed in a situation in which he is receiving noxious stimulation and from which there is no escape. However, he may be able to control his environment or at least predict the occurrence of noxious stimuli. If he does not perceive that he can do either of these things, then the result will be depression. If, on the other hand, he considers that he is able to control his environment or predict events, there will be some degree of anxiety reduction with regard to those events. The information upon which the patient bases his perceptions of his environment may be realistic and factual; if this is so, then the result will be adaptation although anxiety may well exist concerning some aspects of the process. However, if the patient bases his assumptions concerning the control of his illness or its course on inaccurate information, his level of anxiety may be reduced but his behaviour may not be conducive to effective adaptation. This new behaviour however, will be maintained because of the reinforcing nature of anxiety reduction. False assumptions occur when the patient is either given incorrect or insufficient information by significant people in his environment, or when he receives correct information and perceives it ineffectively or incorrectly. There are many factors which impede the patient's interpretation of information. These include lack of comprehension of accurate information as a result of the terminology used; reduction in learning ability due to the patient being very anxious; organic dysfunctions which result in the disruption of the mnestic processes; and emotional difficulties as a result of sensory deprivation, social deprivation and boredom.

It has been demonstrated that patients wish to know as much as possible about their illness (7, 30). It has also been demonstrated that physicians appear to be reticent about informing patients about their illness particularly if they are dying (14, 3). This has also been noted to be true of Health Visitors and patients' relatives (8). Many misconceptions of elementary technical and anatomical knowledge have been demonstrated (30, 4), and it has also been shown that patients have difficulty comprehending physicians' instructions. Ley (28) notes two important factors in patients who do not comprehend information: first, they are not satisfied and second, they are likely to make errors of compliance or refuse to comply. Ley et al (29) have demonstrated that increased comprehension of the illness leads to higher levels of compliance to the treatment regimen.

Janis (23) has suggested that information will decrease distress in patients who are about to undergo surgery or who are about to be subjected to painful or frightening procedures. It will do this by providing information for rehearsal, and by preventing fear becoming too high by eradicating unrealistic imagined dangers. His hypothesis was not borne out by further research; although it was demonstrated that the patients who received information recovered quicker and were in less need of analgesics. Leventhal (27) and Johnson et al (24) have both proposed a parallel response model in which the emotional and instrumental responses are independent. In this model fear reduction need not ensure the control of danger and conversely the control of danger will not necessarily result in fear reduction. Thus to return to the original proposition it would seem that to ensure effective general adaptation the patient would have to learn to control his responses at a variety of levels, but would not necessarily be precluded from adapting in one particular area once control is achieved. It would also seem that accurate information can aid the patient in his control of particular areas.

The problems of sensory and social isolation, restricted mobility and boredom can be far reaching. Heron (21) has noted that marked disturbances of cognition, perception and motor performance can occur as a result of environmental restriction. He observed that as the subjects lay in isolation their thought processes gradually changed and reached a point where somatic auditory and visual hallucination could occur. This has been demonstrated to occur in hospitalised patients suffering from Parkinson's disease (37) and in people on respirators (35). McDaniel (34) states that "much of the emotional distress seen, especially during the acute stages of illness and disability, is due to restricted movement and sensory isolation", although he notes that there is little experimental evidence to support this view as yet. It would seem possible that illness might result in sensory and social deprivation which in turn might result in changes of cognition, which could lead to the development of misconceptions and maladaptive behaviours.

The physical situation a sick person finds himself in will define both his perceived control of his environment and his level of stress. It has already been noted that patients undergoing homebased maintainance haemodialysis are less likely to commit suicide than patients undergoing unit based haemodialysis (1). Burdett (5) in reviewing the literature of psychological aspects of haemodialysis notes that, in general, home-based patients show higher levels of adaptation. He suggests that this is because the patient perceives that he has more control over his illness when he is responsible for his own treatment process. Evidence on this point has been provided by Goldstein and Reznikoff (16) who show a relationship between an external locus of control and a tendency to commit suicide in haemodialysis patients. However, work concerning adaptation to aspects of illness and locus of control has not confirmed (44) hypothesis that there is a relationship between an internal locus of control and physical wellbeing (31; 16). Wallston et al (51) have suggested that the reason why there are findings contradictory to this hypothesis is that the measuring instruments used consider a too generalised response set. They propose that in specific situations such as illness it is more appropriate to use specific expectancy. This would seem reasonable although experimental information is not available. It has already been noted that hospitalisation can generate anxiety and depression (49) and this has been ascribed to the situational stress and isolation inherent in going into hospital. It is likely that a patient in hospital perceives himself as being more helpless than a patient at home. Verwoerdt and Dovenmuehle (49) note that patients in hospital learn to be disabled, and consequently function at a lower level. It is suggested that the physical situation of a patient can have influence on his adaptation by the generation of negative response sets. These response sets will lead to misconceptions and misinterpretations of information.

The following factors are therefore suggested to be of importance when considering a patient's rehabilitation:

a) The patient's perceived control of his illness

b) The information a patient has regarding both his illness and his rehabilitation course.

c) The interpretation of the information concerning such illness and course. Many factors will be involved in how information is interpreted including neurological factors, situational . factors, social deprivation and perceived control.

d) The patient's level of anxiety in rehabilitation may be independent of his instrumental responses.

The importance of a patient's family in aiding any rehabilitation programme should not be underestimated. It has been demonstrated that family support giving encouragement, acceptance and active interest had a significant, positive effect on the patient's progress in rehabilitation. Family empathy defined in terms of understanding the needs of the disabled person was also directly related to successful rehabilitation (41).

The families of sick and disabled people are often under great stress: some authors consider that dialysis partners suffer greater psychological stress than the patient with renal dysfunction (5, 26). It has been pointed out that stress and tension was the major problem of the wives of patients who had suffered myocardial infarctions (12) while the patients themselves saw the major difficulties as being a changed financial situation. It is suggested that stress could be alleviated by providing the patient's family with information concerning the disorder. This would enable the family to comprehend the needs of the disabled person more effectively, and might also result in higher levels of acceptance of the patient, and generate interest in rehabilitation procedures.

THE INVESTIGATION

It is proposed in the present study to observe the patient's response to illness using Pritchard's Response to Illness Questionnaire, the Meaning of Illness Questionnaire (38, 39) and The Health Locus of Control Scale (51). It is also proposed to measure psychological variables using the Zung Depression States Inventory (54), the Rotter(40) I-E Inventory and Manifest Anxiety Scale (47). We also propose to use the same questionnaires with the spouses of the patients and then to ascertain if the results of the questionnaires have any relationship to vocational rehabilitation outcome. If any such inventories prove to be useful in predicting outcome then it might be possible to incorporate these into an assessment procedure for patients referred for occupational rehabilitation. The results may also provide information which would be useful in designing a programme for those patients who will later be considered for vocational rehabilitation.

1. THE HYPOTHESIS

a) Perceived control of illness as measured by the Health Locus of Control Scale will predict the level of occupation rehabilitation.

b) The factors related to the response to and meaning of illness isolated in the scales developed by Pritchard will predict response to Occupational Rehabilitation.

c) Depressive symptomatology will predict adverse levels of occupational rehabilitation.

d) General measures of perceived control will predict occupational adjustment.

e) Reported levels of anxiety will predict the level of Occupational Rehabilitation.

f) That a high correlation between patient results and the results judged by the family will predict rehabilitation.

2. THE METHOD

a) Design: it is proposed to undertake a within subjects observational study on people disabled by physical illness, mental illness or physical handicap who pass through the Leicester Employment Rehabilitation Unit, over a four month period. All clinical measures will be made by the Clinical Psychologist in conjunction with the D.R.O. and the Employment Rehabilitation Unit Work Supervisors. All measures of vocational rehabilitation will be undertaken by the Occupational Psychologist in conjunction with the Unit Manager, Social Worker and Medical Officer. In order to avoid bias neither group will have knowledge of each others' results.

b) Subjects: the subjects will be the clients and their families passing through the Leicester Rehabilitation Unit from May to September, 1978. The final population is as yet unknown. Subjects will be obtained by direct request as they pass through the Unit.

c) Assessment instruments: clinical scales:

(i) Health Locus of Control Scale (51). This is an 11 item scale using a Liker type 6 point format which purports to measure the patient's perceived control of his illness. Construct validity studies have demonstrated that patients who held internal locus of control beliefs and who valued health chose to expose themselves to more information about a given health condition and these patients would take steps to better their environmental conditions.

(ii) Response to Illness Questionnaire (38, 39). This is a item experimental devised to investigate various aspects of reaction to illness. Validation studies are not yet available.

(iii) Meaning of Illness Questionaire (38, 39). A series of semantic differentials devised to measure the meaning a patient attaches to various aspects of his illness. Pritchard (38, 39) has isolated seven dimensions of illness behaviour using these two questionnaires. They are: hopeless defeat; anxious preoccupation; outward hostility; helpless loss; challenging appraisal; illness as an enemy; paranoid withdrawal.

(iv) Zung Depression Inventory (54). This is a 20 item inventory using a four point format with items relevant to depressive symptomatology. It has been demonstrated to differentiate depressed patients from non-depressed patients (p .01). Reliability has been demonstrated by its internal consistancy with split-half correlations in which p 0.01.

(v) Rotter I-E Inventory (40). This is a 29 item questionnaire which purports to measure the perceived control the subject has over his environment. Reliability and validity data are provided by Rotter (40).

(vi) Manifest Anxiety Scale (47). This is a 50 item questionnaire about anxiety symptoms that the subject completes as 'true' or 'false'. Reliability and validity data are provided by Taylor (47).

3. OUTCOME MEASURES

Two measures will be used on five point scales. They will be: severity of disability; level of occupational rehabilitation. The former will have a range from mild to severe, the latter scale will be based on the type of work situation in which the patient is placed and the hours worked.

4. RESULTS

The results will be presented in full at the European Conference on Rehabilitation. It is hoped to provide slides of the statistical analysis of the data.

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THE CASE OF THE SINGLE CARING DAUGHTER

Miss Heather McKenzie

The rise in the number of very old infirm people is both a great strain on health and social services and upon those who are doing the caring within the home environment. Among those who make a valuable contribution to the care of the old and infirm are single women. Many of them virtually sacrifice their own individuality and financial security to look after their parent. This undertaking can seriously affect the whole qualify of the carer's life. Further, even on the death of the parent, the carer is left without a vocation, lonely and physically and mentally exhausted. There are supportive services, yet they generally do not intervene at the preventive stage, before the caring pattern has been established. The single caring woman is generally left to cope alone.

By the 1980's there will be more than nine million old age pensioners in Britain, with some 700,000 of them needing some form of daily attention from health workers or relatives, or both [1] One group of relatives who will undoubtedly continue to shoulder part of the burden of care of the disabled elderly is the single woman.

There are two distinct entities in a caring relationship - the elderly dependant and the carer; each with its own needs, and each with a vested interest in retaining its self identity, despite the bond of affection that usually exists.

These premises have to be remembered when examining the intense interaction which is apt to develop during the caring process.

Methodologically one must look first at the original reasons for undertaking the caring, and secondly at the progressive caring pattern. Generally, the carer has one of the following motivations - a lack of facilities within the community to take care of her parent, a sense of familial obligation, societal pressure, or in a minority of cases, the desire to be relieved of a hitherto unbroken work period.

The elder will have reached the dependent stage of life after having progressed through a self-sufficient and/or economically active lifespan. The carer, here an adult child, will previously have been dependent upon the old person, and now roles will be reversed, and this reversal can have a traumatic impact on their inter-relationship.

We are assuming for the purposes of this paper, that the carer has not had any training in home nursing, guidance in how to protect herself against the problematical areas of the caring role or that the home has not been structually adapted to relieve part of the burden. We must be reminded that the societal structure in which twentieth century caring

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[1] Projected from Family Policy produced by Conservative Research Dept. published 20 February 1978 p.56

Miss Heather McKenzie LL.B Administrative Director National Council for the Single Woman and Her Dependants takes place is based upon quite different tenets from those of earlier times. Today the majority of us must be economically active, in order to be self-sufficient. Therefore, when the elderly dependant requires constant care and attention and can no longer be left 'at risk', the potential carer is faced with a critical decision - whether or not to sacrifice financial and emotional independence to fulfil this duty; whether to try to combine the economically active and the caring roles; or whether to permit her parent to be admitted to sheltered housing or Part III. If either of the latter two decisions is taken, a severe guilt complex often results. In the other situations, loss of identity, isolation, and financial anxiety are the most formidable challenges.

Preservation of self identity is perhaps the most difficult challenge for those off-spring who have not effectively severed the umbilical cord. In their case, there will be a greater likelihood of their identity merging with the increasing needs and demands of their dependant. As Mary Woolstonecraft commented in her 'Vindication of the Rights of Women, in the chapter on duty to parents, 'a slavish bondage to parents cramps every faculty of the mind'. However, we know that every caring situation has two distinct possibilities - a rewarding interrelationship or a mutually destructive interrelationship.

Where the initially independent but now disabled parent becomes a dependant, her adjustment to the role can be without demur, or alternatively, the psyche can rebel, and rebellion results in deep-seated resentment, which can be manifested in demanding, disagreeable behaviour, or depression. When an old person becomes disabled, any domineering trait can, and often does, become more pronounced. For the carer, the sudden reversal of roles, for which she is both untrained and emotionally unprepared, may produce inner conflict. Her own physical and emotional needs may be correspondingly suppressed, and the situation may often be accepted only by an attitude of resignation, a tendency to suffocate the parent with too much attention, or a compulsive enslavement to the role, which in turn may produce exhaustion and anxiety.

For those who have formerly established a lifestyle of their own, succumbing to the societal or familial pressure to return to the caring scene, may cause frustration and anger. Some carers assuage their guilt at having these feelings by perhaps falling into depression, which may manifest itself in physical debility.

Once a caring pattern has been set, and intense interdependence has been built up, the resultant isolation it produces may create an atmosphere of abysmal loneliness and introspection. Many carers subjected to a deteriorating and prolonged one-to-one relationship, particularly where a dependant is suffering from senility, finally collapse mentally and physically under the strain. As the situation deteriorates, the avalanching feeling of being unable to cope with the dependant's worsening physical condition, or changed personality, and their own lack of relief from the scene, may bring some carers to vent their acute anxiety through the medium of physical assault on the old person. Such reactions later turn to profound guilt and shame, and the carer retreats into the sheer hopelessness of the situation.

> 'And the awful thing is that the more one may love one's parent, the more one feels ashamed of one's feelings of resentment'.
>
> 'Much of the time I feel nearly at the end of my tether, and the least provocation may bring on depression or outbursts of temper. On one occasion, breaking a broom handle - before bursting into tears and then feelings of guilt'. Being polite and putting on a cheerful face to the outside world is also at times a strain, and I'm afraid I might scream or swear or in some other way disgrace myself in public'.

From the financial point of view, the carer will necessarily have to adjust to enforced reduction of income, and a reduced standard of living as a consequence.

The sword of Damocles which hangs over every carer's head is the fear of having to resort to 'sustenance by supplementary benefit'. This plunge from self-effected self-sufficiency through economic activity, to state support, can debase a carer's self-image. Research has indicated that there are long-term financial anxieties inextricable from the caring responsibility. The Invalid Care Allowance is a poor substitute for an average wage or salary.

The demise of the dependant brings other problems, amongst which are the far-reaching effects that can result from lack of foresight on the parent's part to provide security of tenure for the carer in the family home. Another problem occurs where intense interdependency has been built up during the caring period and outside help has been fiercely rejected by both parties. The long-term carer may feel she no longer has any role left in life. The carer who entered the role reluctantly, may not be able to cope with the conflicting feelings of guilt and relief, and the acute awarenesss of the sacrifices she has made, and may retreat into mental or physical breakdown. In all probability, the carer will be without a vocation, have lost touch with friends and confidantes, and her grief and isolation will be exacerbated by not having anyone available to talk to. Hence the normal bereavement reactions are less easy to bear.

Let us now turn to the main external support mechanisms, looking at how they ideally alter the interdependency pattern, and what their actual overall impact is. The Primary Health Care Team comprises the General Practitioner, Health Visitor the District Nurse, Social Worker, Home Help and Volunteer.

The most important link in the caring chain should be the General Practitioner. In an ideal world, the GP should know the particular physical and psychological problems of both parties, but the Primary Health Care Team of community medicine often divorces GP, patient and carer. Again, few GPs have any intensive training in geriatric medicine (and unfortunately sometimes have no interest in it) and along with welfare workers, leave it to Miss X to cope alone.

Miss X, on the other hand, may be suffering greatly from a parent's unco-operative and intolerable attitude or the increasing demands of caring and be near physical or mental breakdown. Unless she is sympathetically 'drawn out' she will never admit her problems to her GP. Carefully handled, she can be helped and thus preventive intervention can avoid breakdown and re-establish tolerable familial interaction.

The next vital link in the supportive services chain is the Health Visitor, whose comprehensive training and experience should equip her to detect changes in the elder's physical and mental condition, and in the event of deterioration, forewarn and support the carer to cope with these changes, and point her towards those supportive community resources that do exist.

Possibly the person whose help is most readily accepted by the caring woman is the District Nurse. Initial acceptance of her advice and guidance on practical nursing matters can sometimes pave the way for acceptance of counsel in the more complex matter of emotional and psychological conflicts, which can develop within the caring situation.

The Social Worker's part in this support system can be critical. Her intervention can result in provision of practical or financial benefits by the social services department. Where an elder has become withdrawn, or impossible to cope with, she can arrange admission where appropriate, to a home or hospital. She can also advise on emotional conflicts and problems which crop up in the caring scene.

Another important support is the Home Help - but because the carer is an apparently able-bodied woman, her application for such assistance is often refused. A home help can be invaluable in breaking an isolation pattern while simultaneously relieving the overall caring burden.

Increasingly, the volunteer is playing a more pronounced role; her intervention can alleviate isolation, provide much needed relief, and she can assume the role of confidante.

Ideally, to have the full positive impact, all these support services should be properly liaised. It is important that this kind of multi-disciplinary intervention should occur before a set pattern of behaviour between carer and dependant has been established. Once interdependency has become firmly rooted, penetration can prove impossible.

In conclusion, what are the single woman's real options? An elder's sudden frailty may result in her taking an immediate and possibly ill-considered decision, which in turn can produce traumatic changes in her whole quality of life. Not all women are born carers; some find caring rewarding and are eternally happy that they have assumed that role; other carers find caring a hardship and a quite intolerable burden.

There seems to be a silent conspiracy to leave the otherwise apparently unencumbered spinster daughter to get on with the job. The isolation, anxiety and hopelessness of the situation are hers to cope with. Do the professional and statutory bodies really want to know? To quote Dr Muir Gray, 'support for the supporters must be a key-note for the 1980s' [2]

[2] Dr Muir Gray 'The Breaking Point' Community Care 21 June p.16

References for this paper are essentially based on research carried out by N.C.S.W.D since its inception in 1965

Seminar 3

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SEXUAL PROBLEMS
Chairman: *Mr. R. Travers*

The Problems that Parents Experience in Coping with the Sexuality of their Disabled Children
Dr. Wendy Greengross

Sexuality and the Handicapped
David Stock

EMOTIONAL PROBLEMS
Chairman: *Mr. J. Sarney, CAE*

The Effects of Disability to the Concept of Social Psychology
Mr. John Stewart

Disabled Families
Mrs. E. Topliss

PLENARY SESSION
Chairman: *Dr. the Hon. Harry S. Y. Fang*

The Disabled Elderly in a Changing World
Dr. R. Glyn Thomas, DPH

International Year for Disabled Persons—1981
Mr. Esko Kosunen

MOBILITY HOUSING

Selwyn Goldsmith*

ABSTRACT. This paper describes the work done in England on the formulation of standards for and the promotion of mobility housing, which is ordinary housing designed to be convenient for disabled people to live in or visit. Designed to the same space, amenity and cost standards as ordinary public sector housing, its essential characteristics are that entrances and principal rooms are accessible to wheelchairs and dwellings can be used by disabled people without the need to negotiate steps or stairs; these conditions can be applied to a variety of housing types. The paper suggests that there is a lesser need for special housing than was formerly supposed, and that mobility housing has the potential to cater for the great majority of disabled people.

Mobility housing is ordinary housing which is convenient for disabled people to live in or visit. Its essential characteristics are that the entrance and principal rooms are accessible to wheelchairs, and it can be used without the need to negotiate steps or stairs. In this paper I shall discuss the significance of mobility housing, in terms of its practical potential to meet the housing needs of the great majority of disabled people, and also in terms of the policy shift it represents - away from the concentration on special solutions to the provision instead of normal solutions, whereby normal parameters are extended to cater for disabled people. The paper looks at the background to the introduction of mobility housing, the research inquiries undertaken for it, the results so far, the lessons which have been learned and the conclusions to be drawn.

My position as author of this paper needs to be made clear. I am employed in the Social Research Division of the Housing Development Directorate of the Department of the Environment, where I advise on housing services for disabled people. As a professional officer in the Department, it is not my job to make policy decisions - this is the responsibility of policy administrators, and in the course of this programme of work there has been close co-operation between us. I ought also to note that the Minister of Housing Mr Reg Freeson takes a special personal interest in housing for disabled people, and the achievements made in recent years stem in large part from the drive he launched in February 1975 to increase disabled housing provision throughout the country.

The idea that ordinary housing should be conveniently designed for disabled people was not something thought up in the Department of the Environment in the 1970s: it had been around since the late 1950s when people first began thinking about making our physical environment better for disabled people to live and work in. The issue was one of converting the idea into practical action.

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Looking back, the realisation of the objective was impeded by the tactical directions we followed on housing for disabled people in the 1960s. Impressed by the obvious problems of severely disabled people - the paraplegic housewife for example with a young family - we tended to suppose that the way forward was to design housing to suit chairbound people, and it would then be convenient for all others. Advised by disabled people and organisations working on their behalf, housing authorities began to build special housing. Dwellings had wider doors, expansive circulation spaces, and specially planned and equipped kitchens and bathrooms. Because these dwellings were special they were often planned in little groups, for example around a cul-de-sac which became a disabled colony. Self-evidently this was not normal housing.

There was also an unexpected phenomenon. What sometimes happened when special housing schemes were built was that local authorities found it difficult to locate suitable disabled people - such as paraplegic housewives - who wanted to live in their special housing. This could not always be simply explained away by alleging that housing authorities did not look far enough.

What was clear however was that many disabled people, while not needing special housing, did need suitable housing, most importantly without stairs. The kind of households that come to mind are those where there is an elderly person who is arthritic or who has had a stroke, a mentally handicapped child, an adolescent spastic person, or a disabled adult able to walk only with difficulty. Often these people might use a wheelchair, but only when outside their home. These kind of people are far more numerous than those who are confined to their wheelchairs and who do need special housing.

When we began to prepare design guidance for mobility housing the basic principle was that this was to be ordinary housing, planned to the same constraints as other ordinary housing. We ought not for example to advise that it should incorporate extra space which would make it more expensive than ordinary housing. In Britain new public sector housing - meaning housing built by local authorities or housing associations - is financed with a substantial subvention from central government. In order to receive this government subsidy new housing has to conform to prescribed amenity and space standards - known as Parker Morris standards - and has to be built within cost limits known as the housing cost yardstick.

In respect of space, Parker Morris standards require that dwellings shall have a minimum overall area according to the number of people to be accommodated. A two-storey house for 5 people has for example to have an overall area of not less than $86.5m^2$, and a flat for 4 people has to have an area not less than $73.5m^2$. It is a fundamental precept of efficient and economic house planning that, to maximise usable living space, circulation areas are kept to a minimum - a condition difficult to reconcile with the requirements of wheelchair users. If we were to be able to advise that mobility housing would be accessible to people using wheelchairs, we would need to determine whether wheelchairs could, even if only with difficulty, be manoeuvred within the typical circulation areas of Parker Morris dwellings. What we did not wish to happen was living areas made smaller on account of larger circulation spaces.

In ordinary housing the standard door for main rooms is one we call a 900 doorset, meaning that the structural opening is 900mm wide, the door is 826mm wide and the clear opening width is 775mm. The standard passage width is 900mm. So we carried out a careful study at the Institute for Consumer Ergonomics at Loughborough to establish whether standard wheelchairs available in the UK for indoor use could be manoeuvred from a 900 passageway through a 775 opening. With minor qualifications we found, surprisingly, that they could.

So the requirements for mobility housing which evolved were that entrance doors should have no steps and that doors to principal rooms should have 900 doorsets, with passageways minimum 900 wide. For complicated planning reasons we could only advise, not require, that bathroom and wc compartment doors were also 900. Understandably this provoked criticism when the guidance was issued, but most of the mobility housing schemes of which I have seen plans do have 900 doors to the bathrooms.

The basic rules of accessible entrance and wheelchair access to principal rooms means there are four types of dwelling which can be built to mobility standards. These are

i. bungalows

ii. ground floor flats

iii. flats served by lift, in which case the lift must be large enough for a wheelchair

iv. 2-storey housing, where the bathroom and at least one bedroom are at ground level.

If a substantial proportion of our new housing were still being built in high-rise blocks with lifts we should be able to provide a large amount of mobility housing in this form. But in recent years there has been a strong reaction against high-rise blocks - primarily on social grounds - and the consequence is that nearly all our new housing is low-rise of 2 or 3-storeys, with no lifts. Our family units are generally 2-storey houses with bathroom and all bedrooms upstairs.

With this in mind we reviewed our criteria for mobility housing. We decided that if 2-storey housing were designed with an accessible entrance, with wheelchair access to ground floor rooms and with a downstairs wc compartment, it could be designated as mobility housing if it had a straight flight staircase on which a mechanical stairlift could, if the need occurred, be installed to give access for a disabled person to bathroom and bedrooms upstairs. This has significantly increased the scope of mobility housing.

When we looked at the cost implications of mobility housing it was clear there was no cost penalty on account of internal planning. It was however the case that the provision of a ramped or level access with low entrance threshold was more expensive than the standard provision of two steps and a standard threshold sill. So it was agreed that for dwellings designated as mobility housing an allowance of £50 - raised this year to £60 - should be added to the cost yardstick. When the overall cost of an average dwelling is now £12 500, £60 is so negligible that it is improper to say that mobility housing costs more.

The concept of mobility housing was introduced in a departmental circular issued in May 1974. Records of mobility housing planned by local authorities and housing associations have been kept since the beginning of 1975 (table I). The official statistical returns indicate that the number of mobility housing units so far built or proposed in England is of the order of 24 000.

These figures are I think very encouraging. Housing authorities and architects have responded I think because they want to provide housing suitable for disabled people, and they recognise that building to mobility standards is a sound way of doing it. At the same time as mobility housing has been promoted, local authorities and housing associations have been encouraged to provide wheelchair housing where it is needed. The figures in the table show that the quantity of provision has grown steadily in recent years.

You may inquire why we do not make mobility housing standards mandatory for all public sector housing where it is practicable. It could be that in the future action might be taken, but for the present there are no proposals. In the UK the statutory responsibility for meeting housing needs rests with local housing authorities, and it is not the job of central government to dictate to local authorities how they fulfil their duties.

You will have noted I have not made any estimates of the number of handicapped people who need mobility housing or what targets should be set for local provision. On the estimation of need we examined all relevant data, in particular the national survey "Handicapped and impaired in Great Britain", published in 1971. But it was impossible to apply this data meaningfully to housing provision. In the paper I wrote in 1974 on mobility housing I suggested that perhaps 15% of those categorised as "impaired" needed to be in mobility-type housing, representing 1% of the total population, but the estimate was very crude. And it would not of course be sensible to translate this into action by saying that only 1% of our new building programme should be mobility housing. Nor should we ignore the needs of disabled people who want to go visiting, and can do so if dwellings are designed to mobility standards. On the basis that mobility housing is ordinary housing, the policy has always been that it should be provided wherever practicable. Many local authorities are now doing this with instructions from housing committees to their architects.

In this paper I have been discussing the provision of mobility housing in the public sector. But the principle can equally be applied to private housing. The National House Building Council - which advises developers in the UK on standards for private housebuilding - is currently preparing guidance. With the growing political and public awareness we now have of the housing needs of disabled people we can expect private developers to be making a steadily increasing contribution.

To summarise and conclude, there are four observations:

i. a large proportion of the ordinary housing we build can be designed so that it is convenient for disabled people.

ii. in the practical application of this objective, criteria for disabled people ought not always to be pre-eminent; they should be balanced by prevailing planning and financial constraints.

iii. in respect of assessing the need for this kind of housing, information from general surveys of the disabled population is of little practical relevance.

iv. political awareness of the housing needs of disabled people, for example in the housing committees of local authorities, can greatly assist the realisation of successful programmes.

Table 1 Public sector housing for disabled people in England 1970-78

The figures below are drawn from the statistical returns made each quarter to the Department of the Environment in London by local housing authorities and housing associations. Mobility housing figures relate to England only, from the date (January 1975) when figures were kept following the introduction of the concept in May 1974. Wheelchair housing figures relate to England and Wales, from the time (August 1970) of the implementation of the Chronically Sick and Disabled Persons Act.

	MOBILITY HOUSING		WHEELCHAIR HOUSING	
	Proposals	Completions	Proposals	Completions
1970			132	-
1971			502	16
1972			482	149
1973			515	208
1974			608	327
1975	1213	-	1023	613
1976	9926	172	1267	657
1977	9283	1250	1354	674
1978 (first quarter)	3455	745	412	146
Total	23877	2167	6295	2790

References:

1. Department of the Environment. Housing for people who are physically handicapped. Joint Circular from the Department of the Environment (74/74) and the Welsh Office (120/74). HMSO, London, 1974.

2. Department of the Environment. Wheelchair and mobility housing: Standards and costs. Joint Circular from the Department of the Environment (92/75) and the Welsh Office (163/75). HMSO, London, 1975.

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HELP FOR THE DISABLED AND THEIR FAMILIES - A DOMICILIARY PHYSIOTHERAPY RESEARCH PROJECT

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In 1974 it became clear, following the opening of the new department at Northwick Park, that there were difficulties in transferring heavily disabled patients to hospital because of the irregularities and problems with the ambulance service. It was, therefore, decided to initiate a domiciliary physiotherapy scheme and the advantages of this soon became apparent. The relevance of rehabilitation exercises directed towards the patients own environment became clear and it was possible to involve both the family and the local authority nursing and social services far more directly into the rehabilitation aspects of the management of the patient. Physiotherapists became more aware of the community needs and the community aspects of management of patients in the home. An "At Risk" register is evolving from those patients seen and identified by the therapists in whom there may be the possibility of increasing disability at a later stage.

For many years people have felt that physiotherapy services should be concentrated in the District General Hospital. There is a national shortage of physiotherapists and therefore scarce resources were thought to be of greater value when concentrated at one source. It had also been suggested that the cost of running a domiciliary physiotherapy service would be daunting and that the number of patients requiring home treatment might rise to a far greater number than could be coped with by the available resources. The Tunbridge Committee report in 1972 felt that it was an uneconomic use of scarce skills for physiotherapists to give treatment in patient's homes. They did, however, go on to say that home visiting should be undertaken by hospital physiotherapists shortly before or after the patients discharge from hospital in order to give advice to patients or their relatives, or, to make arrangements in conjunction with the community team for simple remedial exercises, home aids or equipment. It was felt that the visiting physiotherapist should be attached to the hospital and work under the supervision of the Consultant in Rehabilitation,who would also arrange for domiciliary assessments or visits by the remedial team to make suggestions about rehabilitation at the request of the General Practitioner.

(1) Rehabilitation. Report of a Sub-Committee of the Standing Medical Advisory Committee (1972) Tunbridge Report, H.M.S.O. London Domiciliary Physiotherapy, 88-89.

REASONS FOR STARTING

When the Northwick Park Hospital Rehabilitation Department was commissioned in 1974, it was found, soon after the opening of the unit, that many of the heavily disabled patients, who required a two-handed ambulance were not being brought for treatment and, of those who were brought, many were kept waiting for collection and became very distressed. Many of the patients were too tired to carry out their exercise programme

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after the journey, some were brought in on anirregular basis and some not at all. Other patients had often waited ready at home to attend the hospital unaware that there was to be no ambulance at all that day.

Our plans for a daily intensive programme of treatment, with a lunch and rest at midday soon became a theoretical dream and the proposed help and advice to the relatives and nursing services, either accompanying or meeting up with the patient in the hospital department again fell through, as, if the patient was brought in there was no room for an escort, and the nursing services could not fix a time to meet as we could not guarantee the arrival of the patient for an appointment given in advance.

GROUND WORK

We decided to explore the possibility of running a hospital based domiciliary physiotherapy service and discussed this suggestion with the General Practitioners and with the Greater London Association for the Disabled who felt that they all knew of large numbers of heavily disabled patients needing attention at home and advice. The District Nursing Service also provided us with statistics relating to the numbers of patients whom they were visiting and who might require help from the physiotherapist. It was soon realised that the previous idea of treating patients in the hospital environment with its large gymnasium with no carpet or furniture and a straight staircase with a rail at each side,was not, in fact, a realistic method of reproducing the problems encountered in the home environment, and that the relatives and District Nurses had a far more difficult task than we had envisaged.

It was also realised that part-time physiotherapists could be employed working flexible hours to suit both themselves and their patients and,as they were available out of the normal routine hospital working hours, they could contact relatives when home from work and they could also contact Nursing Services and meet directly at home.

RESEARCH

The above suggestions were put forward to the Department of Health and Social Security and an application to study the value and cost of running a hospital based Domiciliary Service was accepted for a three years study in 1976.

POPULATION

The population of the Harrow Health District is 220,000 and the environment is that of an essentially urban mixed community, with reasonably satisfactory housing spread over an area of approximately 9 square miles.

Patients selected for the project are those with either a chronic disabling disease or a short term immobility problem, resulting in difficulty in travelling in an ambulance where the help of two men are required, or where travelling would cause undue distress to the patient and where advice to the spouse or other carer at home is felt to be more appropriate in the home environment. This is also carried out by the domiciliary physiotherapy scheme.

REFERRALS

These come from several sources :-

I. Hospital Medical Staff may refer :-

- (a) patients seen in the out-patient department
- (b) patients being discharged from the wards
- (c) patients seen directly on a domiciliary visit

II Physiotherapists may refer patients seen in the hospital department who are :-

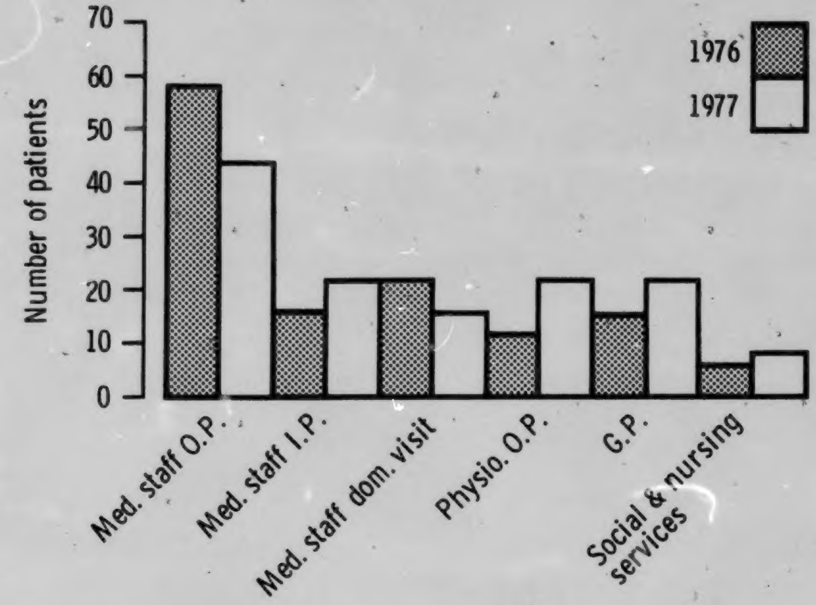
- (a) considered unsuitable for transport, especially when they arrive in a distressed state when transport has been provided
- (b) when being brought in on a very irregular basis and who are not, therefore, deriving the maximum benefit from treatment
- (c) where a follow-up exercise programme and assessment of the home environment is considered of therapeutic value

III The District Nursing Services may refer patients to the Domiciliary Scheme through their own General Practitioner.

IV Social Services may refer to the Domiciliary Scheme or go through the appropriate General Practitioner.

V General Practitioners may now refer directly to the Service having accepted the policy on which the service is based, often referring patients known to us but following a recently acute incident on an already present chronic disability. For example, a recent fall or a post-influenzal epidemic making a patient with multiple sclerosis more disabled than he was before.

Fig. i
Sources of referral 1976-1977

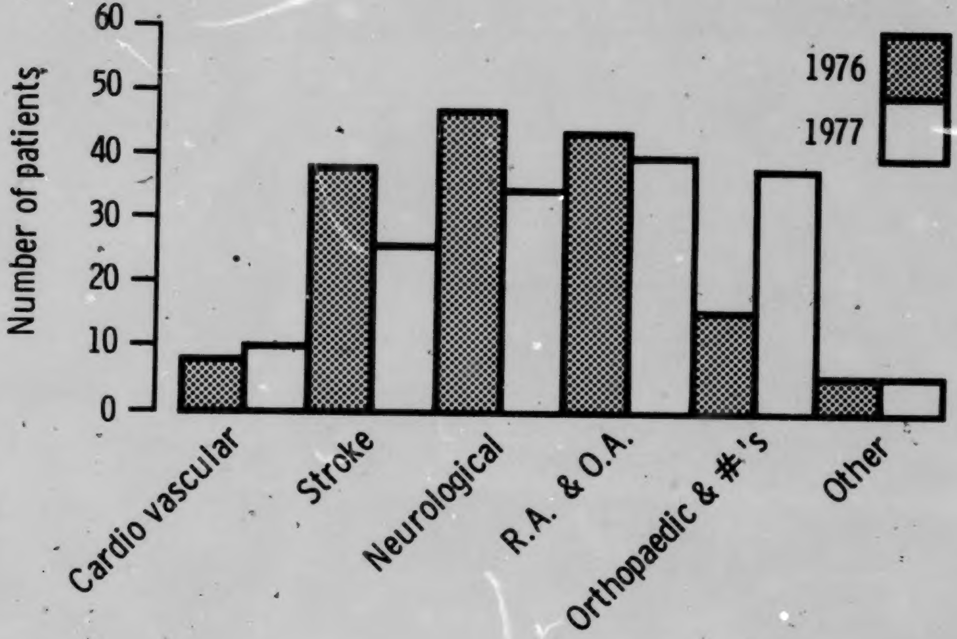


DIAGNOSTIC GROUPS

These fall into the following categories :-

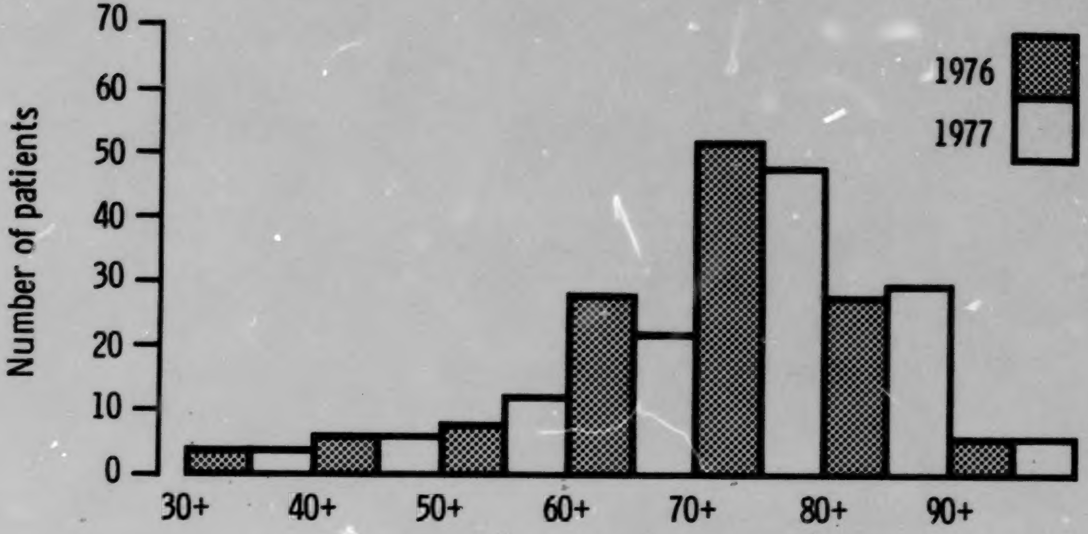
I	Neurological (such as Multiple Sclerosis, Parkinson's Disease, Motor Neurone Disease etc.)
II	"Stroke"
III	Rheumatoid and Osteoarthritis
IV	Circulatory Disease, including amputations
V	Respiratory Disease, i.e. Chronic Bronchitis
VI	Fractures in the confused and elderly arthritic are also treated at home on occasions

Fig. ii
Diagnostic breakdown 1976-1977



The average age of the patients is high. The mean lies roundabout 75 years.

Fig. iii
Age distribution 1976-1977



REASONS ARISING DIRECTLY OUT OF IMPAIRMENT

These include :-

I To maintain mobility and independence in daily living activities

II Where an acute crisis arises in addition to known disability

III Where advice is needed for the home "carer"

IV Where follow-up confidence is needed after discharge from hospital

V Where distress is caused to the elderly and confused patient by bringing them up for out-patient treatment

VI Where advice is needed on the use of aids and appliances or there is a need to supply these.

Fig iv Table showing reasons for Treatment for Domiciliary Physiotherapist

		1976	1977
a.	Maintenance of mobility and independence of Chronically disabled.........	90	69
b.	Environmental difficulties, not reproducible in hospital department..........	71	62
c.	Acute crisis arising from severe disability..	35	20
d.	Immediate continuation of treatment on discharge after major surgery.............	8	14
e.	Advice and education to patient carer........	61	50
f.	Advice and supervision with regard to appliance and aids........................	70	62
g.	Advice and supervision on daily living activities..........................	61	45
h.	Routine check-up at three month intervals...	14	2
i.	Routine check-up at six month intervals......	6	4
	Other......................................	10	

NB nearly all patients had more than one reason arising directly out of impairment.

NUMBER OF PATIENTS SEEN DURING 1976/77

It can be seen from Figure (i) that there has not been a sudden influx of referrals during 1977 as forecast, and it is reasonable to assume that the demand is now being met and that a plateau has been reached in the terms of reference for this service.

Fig. v	1976	1977	TOTAL
Total Miles Travelled..	5457.10	5962.67	11,419.77
Total Hours Worked.....	1239hr.30m.	1369hr.35m.	2609hr.05m
Total Patients Visited.	933	1102	2035
Average Time of Patient Visit..........	48hr.21m.	48hr.21m.	
Total Treatment Time...	755hr.32m	879hr.40m.	1635hr.12m.
Total Clerical Time of Physiotherapist.....	250hr.38m.	233hr.25m.	484hr.03m.
Total Travelling Time..	233hr.20m.	256hr.30m.	489hr.50m.
Average cost per Treatment Visit........		£5.92	

Fig. v Table showing number of patient visits, hours worked, miles and time spent travelling and average cost per treatment

There is, at present, no waiting list for treatment and any acute referrals are seen the following day.

ORGANISATION

The Physiotherapists, three Seniors, working flexible hours up to a total of 36 hours per week each or 144 hours per month, meet with the District Physiotherapist each week in the Rehabilitation Department. New patients are discussed and assigned on a geographical and zoning basis,previous assessments and treatment programmes are discussed and decisions are made about progress and further management.

General Practitioners are regularly informed by the use of detailed assessment charts. The recommended actions suggested by the Physiotherapist are implemented either by personal contact with the Family Practitioner or by calling at the surgery and speaking personally to the Practitioner or by the telephone.

Occupational Therapists working for the Social Services [illegible] the District Nursing Services become more personally involved with the physiotherapists through arranging joint visits to the patients home and to the hospital department,and useful contacts between the professions have been made and understanding is continuing to grow.

fig. vi Table showing Functional Assessment Chart

Getting down to the floor	
Rolling to the right side	
Rolling to the left side	
Bridging	
Sitting up	
Crawling on all fours	
Walk on knees	
Half kneeling on right knee	
Half kneeling on left knee	
Getting up from floor	
Balance in standing	
Balance in sitting	
Transferring from chair to chair	
Transferring from chair to bed	
Transferring from bed to chair	

Scores:
0 - Impossible
1 - Assistance & use of aid
2 - Independent with use of aid
3 - Independent
4 - Unable to attempt due to comprehensive difficulties

Fig vii Table showing A.D.L. Chart
(Activities of Daily Living)

A.D.L. Performance by Patient

		hospital/	home
1	Transfer Chair/bed		
2	Dressing		
3A	Bathing		
3B	Washing		
4	Using Lavatory		
5	Continence		
6A	Teeth		
6B	Grooming		
7	Transfer floor		
8	Preparing food		
9	Use of taps		
10	Cooking		
11	Feeding		
12A	Walking		
12B	Walking 15 yards		
13A	Stairs (up)		
13B	Time		
14A	Stairs (down)		
14B	Time		
15	Walking (outdoors)		

ADL Scores:
1 - Total independence
2 - Partial independence
3 - Total dependence
4 - Not attempted

TREATMENT GIVEN

These include :-

I Active and passive exercises

II Advice on transferring and lifting for the patient carer

III Advice on the provisions of aids and appliances

IV Breathing exercises and postural drainage

Fig viii Table showing Treatment Outcome

	1976	1977
To discontinue - improved	50	33
To discontinue - treatment inappropriate	17	27
To continue - improvement possible	8	0
Referred to Rehab Dept as O.P. - improvement possible	23	14
Admitted for In-Patient - improvement poor	17	6
Placed on At Risk Register	22	6

Fig ix Table showing Involvement of Patient with other Community Agencies

	1976	1976	1977	1977
	Known	New Referral	Known	New Referral
District Nurse	51	2	44	6
Home Help	39	1	25	1
Social Worker	23	7	28	5
Occupational Therapist	33	28	23	23
Meals on Wheels	11	1	12	3
Appliances	62	7	98	4
Ref Day Centre	15	6	8	1
Part III Accom.				

THE AT RISK REGISTER

This register is kept for all those patients seen with a chronic disabling disease where it is known that in the future, there is likely to be deterioration in mobility and independence and where advice and future help is needed.

These patients are reassessed at intervals of between three to six months to see whether functional status has been maintained and when the progress has been sustained, a great morale boost is given to the patient's family by this visiting, particularly in those who are heavily disabled and normally rather neglected, and when further help is needed this support can be given immediately.

SUMMARY

This service allows a flexible system of care. It also offers advice for the management of the more heavily disabled than previously provided by the hospital service. It allows flexible hours to be worked by experienced physiotherapists with young families. It has improved communications with the services previously based in the community and has given the physiotherapist much wider experience in dealing with the real problems encountered outside the hospital. We feel that the At Risk Register helps all those patients who might otherwise become increasingly immobile and prevents some from becoming a heavy burden both to their relatives and the community. The advice given to relatives on lifting and transferring will also, we hope, prevent back problems occurring in this age group. For patients who are distressed by long hours of waiting for transport and those who are confused by being moved from their own homes, an immediate service at home offers substantial advantages. We hope to continue with the hospital based domiciliary service with financial support from the Harrow District when our research work is completed. The grant discontinues in December 1978, when we will publish a much more detailed and costed report on this service and will, we hope, demonstrate that it is both an economic, useful and necessary extension of the physiotherapy service in the District General Hospital.

WOMEN'S INSTITUTES IN HOSPITALS FOR THE SUB-NORMAL AND CHESHIRE HOMES

NATIONAL FEDERATION OF WOMEN'S INSTITUTES

The National Federation of Women's Institutes of England, Wales, the Channel Islands and the Isle of Man is a mainly rural organisation with 401,000 members in 9,306 Women's Institutes organised into 65 County Federations. It is an educational, social, non party-political, non-sectarian organisation whose main purpose is to improve and develop conditions of rural life.

At the 1957 Annual General Meeting of the NFWI the following resolution was carried:

> 'This meeting urges Women's Institute members to do all in their power to assist in the rehabilitation of Mental Hospital patients by visiting the patients, taking an interest in their welfare, inviting them to Institute meetings and generally helping to dispel ignorance about the mentally sick.'

In working on this resolution, the members went further - the first Special WI was formed in 1958 in Fulbourne Hospital, Cambridge. There is now a total of 60 Special WIs in England and Wales:

33 in Psychiatric Hospitals
12 in Hospitals for the mentally sub-normal
3 in Hospitals for the mentally handicapped
2 in Geriatric Hospitals
2 in Hostels for the mentally sub-normal
1 in a Hostel for Disabled Girls
1 in a Home for the physically handicapped
6 in Cheshire Homes.

Although termed 'Special WIs' these WIs are in fact treated just as any other WI in relation to the Constitution and Rules of the Women's Institutes. Every member pays her full subscription - at present £1.60 per annum - and, as in any other WI, savings schemes can be run to help the member collect her subscription in installments. This has been found particularly helpful in cases where patients have 'pocket money' and might find it difficult to pay out a specified large sum at one time.

In the majority, the membership is usually made up of mostly patients with a proportion from members of the staff, wives of the staff and members from neighbouring WIs. The Officers are seldom patients in the Special WIs, especially those in Psychiatric Hospitals, although this is by no means a rule. One Hospital has a highly efficient Treasurer from among the patients. Nearly every Special WI has patients on the Committee.

As far as possible, meetings follow the normal pattern of a WI monthly meeting, although this very much depends on the actual health of the patients, which in some cases can vary from month to month. In some cases, it is found necessary to adopt a flexible approach to the Rules. The way in which the business of the 'Special WI' is carried out varies greatly according to the type of hospital or institution in which the Special WI has been formed. Although some rely on complete informality of procedure, most try to maintain the normal WI pattern, recognising that business should be presented in as lively and interesting a manner as possible. In a large number of 'Special WIs' members are consulted in the drawing up of the programme for a meeting. Popular talks and demonstrations include films and slides, travel talks, cookery, flower arrangement, crafts, nature talks, skin care and make-up, art (including paper sculpture, fabric printing and collage), music appreciation, local history and others.

Competitions are most popular, with flower arrangements heading the list. Although they have a wide variety to choose from, some Special WIs prefer return visits from speakers whom they have liked, regarding them as friends. In mentally handicapped WIs, programmes in which members can participate are most successful.

All WIs are entitled to send delegates to the Annual General Meeting. They may submit resolutions for discussion and vote on Resolutions which are discussed at the Annual General Meeting. Prior to the Annual General Meeting, WIs discuss resolutions at the monthly meeting held in May. Members of Special WIs enjoy and are extremely interested in discussing resolutions but there is a need to take care when discussing resolutions which might cause distress. Taking resolutions in mentally handicapped WIs has been found to be very satisfying - patients make a great effort to join in.

In most County Federations, a Group comprises several WIs; their existence is not covered by the Constitution but their size and membership allows them to hold larger meetings - usually twice a year - to which a better paid speaker can be invited.

Many of the Special WIs join in outside activities by attending these Group Meetings - indeed, many have acted as hostesses to Group Meetings - and County Federation Council Meetings. Outings are popular and include trips abroad, visits to gas showrooms for cookery demonstrations, jumble sales, places of local interest, picnics, country walks, theatre, cinema and concert parties. In some cases, hospitals pay for, or subsidise, cost of transport to outside events.

In 1974, the National Federation of Women's Institutes was able to issue some general guidance to County Federations. Prior to the issue of these guidance notes, two conferences were organised by the NFWI and attended by representatives of the County Federations and members of staff of the hospitals concerned, with experience in forming and running Special WIs. These conferences proved extremely valuable in the opportunity they provided in sharing experiences. Certain points emerged which would be of help to any County Federation newly planning to form such Institutes. It was felt that the invitation to form a Special WI should come from the hospital or institution concerned. However, it was recognised that in some situations, this would not be possible and it was suggested that where the approach did not originate with the hospital or

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institution, WI members should work as volunteers in these institutions for a period prior to the decision being made to form a WI. It is essential that the invitation to form a WI should have the full and continuing support of the staff and management of the institution and similarly, it is desirable that Special WIs have the sustained support of the County Federation. The co-operation and support of neighbouring WIs is a tremendous help especially when members of these Institutes join the Special WI and help with its running.

Reading the reports from the Special WIs, the feeling comes through that in hospitals where there are short-term patients, the outside contacts provided by their WI life and the activities provided by the Monthly Meetings are of a very worthwhile therapeutic value. Some short term patients were members before they were admitted to hospitals and others join a local WI when they return home. In hospitals where there are chronic patients, the staff claim that membership of a WI helps to keep them in touch with the world beyond the hospital in a way which was not possible before they joined. Although these patients may never return to the community,the work done for them by the WI can be seen as a form of rehabilitation in that more community involvement is made possible.

We are convinced that a normal organisation like the WI,run normally in an institution,brings the community outside much closer and involves our members of WIs in hospitals with the world outside.

WI members are grateful for their welcome into hospitals and tell us that any way they can help in forming and running a Special WI for the patients brings a personal reward and satisfaction which outweighs any effort involved.

WIs in the locality of a 'Special WI' have found that contact with the hospital and WI member patients has helped to allay any fears they may have about life in an institution.

SOME PROBLEMS THAT PARENTS EXPERIENCE IN COPING WITH THEIR DISABLED CHILDREN'S SEXUALITY.

DR. WENDY GREENGROSS

The aims of doctors and midwives is to try to ensure that every woman having a baby remains healthy during pregnancy and labour, and to try to ensure that every baby born is healthy and undamaged.

The fear of almost every mother and father is that they might produce a baby that is in some way imperfect, damaged or disabled. If that happens they start on a journey accompanied by a myriad of problems and although they are often helped with some of these, the problems of sex and sexuality are all too often ignored.

Sexuality is not something that suddenly appears at puberty. It is an integral part of the individual, an essential part of their personality, and it develops as a result of how that individual is treated by others, and how he or she feels about themselves and how they feel about being a man or a woman. We are beginning to know and care much more about the effects of this on the disabled individual; but today I am going to look at this from the point of view of the parents, looking at their problems, their feelings and their needs and trying to give some sort of assessment of why they are apparently left with so many anxieties, and then suggest some ways in which these could possibly be ameliorated.

I think it is true to say that most parents get very little help in this area of need. 'Puberty will be plenty of time to talk about that', well-meaning social workers say; but the truth is that many of the problems arise long before puberty, and even if the problems do not actually arise, the anxiety that parents experience because they may arise is real, painful and destructive; and embarrassed, ashamed, angry and impotent, many parents find themselves thrown onto only their own very limited resources.

The mother of a cerebral palsy daughter told me that when she was told that her daughter was likely to be spastic her first thought was 'She will never get married'; the second 'She will never be able to have sex'. Now whether these judgements were correct or not, or whether the mother in question actually changed her mind is not what I am talking about. I am trying to demonstrate that for some parents at least, the problem about sex and sexuality and marriage may arise very early indeed.

The mother of a mentally handicapped daughter, who walked with the child in a pram to the corner of the road to meet the school 'bus, used to meet the same people day after day; hardly any of them acknowledged her: the few that gave her a rather embarrassed smile, certainly did not dare look into the pram or make any remark about the child. She was treated as though the child did not exist, and because she felt guilty and uncertain of what to do, she colluded in the charade, instead of being able to help the passers-by accept the child and its disability.

The behaviour continues, and we find that only too often the handicapped child is dressed in dowdy clothes so that it should not draw attention to itself. Along with this is a denial of it being either a boy or a girl. Even in these unisex days, small children are brought up conscious of their masculinity or their femininity, even if these are nowadays not so inextricably linked to role definition. But the handicapped child is somehow left in a sexless category - a limbo all its own.,

Mary, aged eight, had cerebral palsy which gave her difficulty in walking and some speech defect although she was of quite normal intelligence. She was very friendly with John who lived next door, and they played together constantly. One day, John's mother said to Mary's mother, that she would rather John did not play with Mary quite so much, because she was afraid that John might get a 'thing' about disabled girlfriends.

Possibly one of the earliest manifestations of sexuality is masturbation, and this is an area fraught with anxiety for many parents, but possibly far more fraught for parents of the handicapped, than anyone-else.

Nearly all children masturbate at sometime or another; it is normal and natural and pleasurable. Most parents are fairly ambivalent about it, and the largest number accept intellectually that there is nothing wrong in the activity, but many of those who accept it intellectually, may have quite different gut feelings about it. The parent of the handicapped child is often, of necessity, far more involved in the child's activities than the parents of an ordinary child.

Stephen, aged three, mentally handicapped, rather immobile, masturbated a great deal. 'You'd better stop him doing that', Stephen's grandmother said to his mother, 'Otherwise they'll take him away and lock him up'.

Peter, aged 10, with early muscular dystrophy, masturbated, and his parents were extremely anxious as to whether this might alter the course of his disease. His parents wanted to ask the doctor whether it would affect him; but there were always other people around when they went to Hospital, and the consultations with their own doctor were infrequent and brief.

Mary, aged ten years, was blind. Her mother was having visitors to tea and Mary had begged to be allowed to join them. She thought that she was extremely well behaved, not interfering with anyone, sitting in a corner, masturbating and listening to the conversation. She did not know that this was not socially acceptable and her mother had never been able to talk about it.

One father of a thalidomide boy without arms, told me that he had taught his son how to masturbate. Many parents of handicapped sons find that they have to change sheets, throw away tissues and are uncertain whether to talk about what's going on or not.

Charles, aged 14 years, became quite upset because he thought he had wet the bed. Now, of course, many boys go through similar stages, but most boys compare notes with their peers and pick up most of their information from the other boys at school: but the handicapped boy is often isolated as well; spending only school hours with his friends, not having the other times when more private conversations and activities could be enjoyed.

So parents become involved, and often anxious, as to whether it is right or dangerous or too frequent or whether it would be better to stop it altogether as they would be unable or unlikely to have sex when they are adults.

One mother of a mentally handicapped boy told me that she had told her son that he was not allowed to masturbate, that sex was not for him and that his reward would be in Heaven.

The washing and toileting of the handicapped youngsters may also often cause embarrassment and anxiety as mother finds that this often precipitates an erection. Sexuality is a very private function that does not usually cross the border of the generations. It is a topic that parents keep to themselves, and a topic that young people do not usually share with their parents, and the mother of the young disabled man who gets obvious large erections when he is washed, may be extremely anxious both about the boy's sexuality and also about her own feelings and she may find that she has to cope with sexual problems in her own marriage which are precipitated by the situation. Most mothers attempt to cope with the situation by infantilising the young man, and refusing to allow either of them to accept the adult sexuality which he is experiencing.

There are just as many problems and difficulties for fathers who, helping with toileting, often have to become involved in their disabled daughter's menstruation, in a way unknown to the able-bodied. They may be experiencing many emotions, such as embarrassment or distaste or they may even find themselves sexually aroused by the involvement: but whatever the emotion, they usually have nobody with whom they can share their feelings: the assumption being made that feelings do not have to come into it - it's a job and it's got to be done.

Now the mother or the father who find themselves in this situation may be anxious or frightened or embarrassed or be experiencing many other emotions and if they have to deny these, the psychic energy used will certainly affect other areas of their functioning; often affecting their own marital relationships or their ability to cope with other children. I have spoken to many parents of handicapped children, and many of them have spoken about their feelings of guilt and their own part in the child's disability. 'How did it happen' 'Could I have done anything to avoid it?' are the thoughts that constantly go through many parents' minds. As most people's feelings about sex and sexuality are extremely mixed; an amalgum of fact, fantasy, myth and inaccurate information; and because many parents were themselves brought up in a sort of subculture that acknowledged sexuality is necessary but enjoying it too much 'as being wrong' it is not surprising that many people have a residual feeling that sex can be damaging or that if you enjoy sex too much you will be punished, and they then equate the child's congenital disability with a sort of retribution or punishment for having and enjoying sex.

None of this is logical but feelings rarely are logical: if parents are given no opportunity to talk about their feelings, to air the anxieties, to hear what they are actually thinking, they may have to continue in their unreal worrying fantasy world. And if they have primitive feelings that in some way their own sexuality has damaged their child, it is not surprising that many find that they are unable to enjoy sex in their own marriage: and at the same time try to keep the child away from sex and sexuality because of damage it can bring in its wake.

So parents often without realising it, keep their children away from learning about sex, from learning about masculinity and femininity. Fortunately, or unfortunately, the parents of the handicapped child wields much more power than other parents do and because they have this power and because most of them wobble miserably between guilt and overprotection, both the child and the parent is eventually losing out. The teenage years should be the years of finding out, of discovery, of reassessment and that requires taking chances. Parents on the whole do not like it, but most parents find themselves in the situation of having to go along, more or less, with the child's needs.

The parents of the average 12 or 14 year old girl, can want to know where she is going, what time she will be home, who she is going with, meet her at the bus stop, pick her up from the Cinema. But by the time she is 16 or 18 the questions get very different answers. 'Where are you going?' 'Oh, out.' 'Who are you going with?' 'Just friends.' 'What time will you be home?' 'I don't know'. A perfectly normal and natural situation. Possibly anxiety-provoking for the parents, but a learning situation for them all. But the parents of the handicapped child who is dependent for mobility, the wheelchair-bound, the mentally handicapped, the blind, always have good reason for knowing where their son or daughter is, and making sure that they do not take unnecessary risks, (whatever those risks may be). So parents often keep their disabled children away from learning situations, situations in which they might have the opportunity to take risks and to learn about themselves both physically and psychologically. They not unnaturally worry about the rough and tumble of play, and that their children may get knocked over, or that damaged limbs may be less able to cope than those of other children. They worry about their children being more likely to be rejected, less able to make friends, more vulnerable when risk-taking than other children. So the children are often kept away from what parents identify as possibly damaging situations. 'They've been hurt enough already,' they say. But possibly it is their own feelings of pain, that they find so difficult to bear. Their own feelings of guilt, that they may be to blame for the whole situation. So disabled children, partly because of their disability, and partly because of their parents' fears, are kept away from situations in which they could learn about themselves and their own sexuality, about being feminine or being masculine. For we do learn about our sexuality in this way. The whole subject of sexuality, masculinity and femininity may give rise to untold anxiety, for most parents still tend to associate sexuality with role definition, and because many find it so hard to believe that their children could have a meaningful adult role in society, they also tend to deny them their masculinity or their femininity.

Jean was 18, spastic, in a wheelchair. She belonged to the local spastic society and was forming a deep friendship with a similarly disabled young man. A holiday was arranged for the group but Jean's parents would not let her go because they did not want the friendship to go too far as 'nothing could come of it'.

Roger had spina bifida and was becoming attracted to an able-bodied girl of his own age he had met at a local P.H.A.B. club. Roger's parents dreamed up a succession of excuses so that they were unable to take him to the meetings for as they said, 'He will only get hurt in the end for she's bound to throw him over, and he's been hurt enough already, poor chap.'

Now I am not suggesting for one second that Roger's parents or Jean's parents were not acting from the highest possible motives. But they were, I believe, overprotecting their child. They had not had an opportunity to talk through their feelings and begin to think about them growing up. They imagined that they were being kind to their children keeping them away from hurt, without realising that they were in some ways adding insult to injury. For one of the lessons that we have to learn in life is that we are not destroyed by pain and by being hurt. If we are forever kept from painful situations we may ourselves begin to believe in the fantasies of others that we can be destroyed by the pain. The lesson that all need to learn is that we can live through pain and painful situations and not be destroyed by them, and when we know that, although situations may still be painful, it is no longer frightening, for it is often the fear that paralyses, and prevents us from operating in the most advantageous way.

One of the most difficult areas for parents of handicapped children, in which they differ from others is that most parents can look forward to a time when their children are likely to be independent, hopefully married with children and have their own home, possibly looking even further ahead even more hopefully to the time that the parents could themselves become dependent or partly dependent on their children. But the situation of parents of the handicapped may be very different, and their future is apparently one of the child (I say the child advisedly because many parents still think of their 30 or 40 year old handicapped son or daughter as a child) being forever dependent. The ever present anxiety of many parents is 'What will happen to our child when we are old or when we die?' If Jean's mother (who was afraid of her friendship with another spastic young man) really can only ever envisage a future which revolves around looking after Jean and can only envisage Jean's emotional involvement, in terms of having to look after Jean's disabled husband as well, and possibly even Jean's legitimate or illegitimate child; she is not really to be blamed when she says, 'Hold! Enough! I really can't cope with anymore'. If Roger's mother can only see her future as mopping up Roger's emotions as he is turned down by a girl after girl, and then eventually 'putting him in a home' because she is too old to go on coping, she should not be blamed either.

We are nowadays, talking in quite different terms, for the disabled themselves, and hopefully we too, are trying to work towards a situation, in which they can be as independent and as self-determining as possible, with opportunities to maximose those abilities that they do possess. I think it is necessary to take parents along with the new thinking. Starting right from the beginning, that although being at home and living there with the family, is usually the most satisfactory place to be in childhood, the young disabled adult may be able to live a far fuller life, away from the family in either residential, or hostel or student accommodation or half-way house or sheltered accommodation or any other type of the multitude that is being set up. I know that at the moment there is not enough residential accommodation available to meet all the future needs, but I believe that parents can be a potent force in demanding that more be set up, if they are given the confidence to know, that this is ultimately the best for their children and for themselves. The separation that takes place between teenagers or young adults and their parents, is a normal and necessary part of growing up, and essential if the child is going to be able to think of themselves as adults, making decisions about their own lives, and taking responsibility for these decisions. We live in a world in which sexuality is an openly talked about part of life.

The young man or woman developing a romantic or sexual attraction does so usually in a world apart from their parents. For some, sex and marriage go together, and sex outside of marriage and before marriage or without marriage would be unthinkable, but there are others who feel differently and either do or would like to explore their sexual needs without being married. There is very often a great deal of difference of opinion between generations, and most people, whether they like it or not, are not involved in the decisions that their young adult children make for themselves. What the eye doesn't see the heart doesn't grieve over. Unfortunately the parents of the handicapped often do find themselves in the sexuality of their children.

Jennifer and Colin were both disabled and had been friendly for many years and had been away on holiday together several times. One day Jennifer asked her mother to take her to the local Family Planning Clinic, as she and Colin had been making love, and wanted to be sure that she did not become pregnant. Some mothers, but very few, find themselves in this situation. Most girls wanting contraceptive advice go ahead and get it. A few might tell their mothers, the largest number do not. So it is easy to see how difficult a situation like this is for Jennifer. But a moment's thought will also show, that this may also be a difficult situation for Jennifer's mother. She may be emancipated, and believe that this is the right thing to do, but she may have quite different feelings about the situation. She may be very religious, and believe that sex before marriage is wrong, or she may think that girls who give into boys lose not only the boy's respect, but also any chance of marriage; what happens if the contraceptive fails and she becomes pregnant, what would the neighbours say if they found out?!!

Probably most would agree that Jennifer has the right to make decisions about her own sexuality for herself, but I am not at the moment talking about that issue. I am talking about Jennifer's mother's feelings, and about what she thinks she should do for the best, and how she makes her decisions without unneccessary hurt, unnecessary pain and unnecessary guilt. But both Jennifer and Colin are presumably heterosexual (straight). What if they are homosexual (Gay)?

We know that probably 5% or 10% of adults are or may be, exclusively gay. We also know that life can be extremely difficult for the young, or the not-so-young homosexual, who may have to go through a great deal of exploration and soul-searching before they can accept and come to terms with their own sexuality. Coming out, telling their parents is usually a much later stage. So disabled homosexuals find themselves with a double handicap, and the parents of the disabled homosexual, with a whole new set of problems, and anxieties and guilt feelings.

But parents often have yet another problem as they feel that society expects them, the parents, to ensure that their children never become sexually active. This may be in part, another area of projection, of the parents' own fantasy. It is however, certainly true that people in general, would rather the disabled were sexless, impotent, and sterile and often subtly pressurise parents, into bringing up children to fulfil these expectations. We know that, unfortunately, the real physical needs, and physical problems of disablement take up the major part of the resources that actually are available. We are, I believe, just beginning to realise that coping with emotional problems, is also important but very often, the resources that are available, are being used to cope with the emotional problems of the handicapped themselves; and the needs of the parents in these areas are being very inadequately met and often completely ignored. There are many things that could be done quite easily, and I think we only need to look at progress in other areas, then apply some of that knowledge to the area of sex and sexuality.

Firstly we need to change some of our own attitudes so that we can all, Doctors, Social Workers, Teachers, Occupational Therapists, Physiotherapists, and the many other professionals who deal with the handicapped, talk about sex and sexuality positively, acknowledging that it is something to be enjoyed, and that many disabled adults could have a fulfilling or enjoyable sex life, if they were more mobile and actually had the opportunity of meeting people so that they could make friends, and then ultimately make some choice of a sexual partner.

We, the professionals, all too often mirror the feelings of the rest of society, who are seemingly afraid of the sexuality of disabled people. (As though, given a taste of sex, they will all turn into sex maniacs and sexual monsters.) If we are honest, we realise that there is often an element of jealousy in our feelings, for we live in a world in which the fantasy of our own sexual prowess is often wildly overated and we may well be made, even more anxious, by the thought that (as one warden of a residential home who was himself having a sex problem put it) 'That cripple can do it better than us'.

So how do we begin to explain to parents some of these very primitive emotions that are possibly very difficult to understand and accept? I think we need to start from a different point, and a more positive one. In this country we have a fairly good record of caring for the disabled. We look after them and we love them but we do not take into sufficient account that it is an uncomfortable place to be, to be always on the receiving end of love. As human beings we have certain rights, and one of those rights is the right to love. Everyone is 'Entitled to Love', not only entitled to be loved, but also entitled to love other human beings as equals, and parents may find it much easier to accept their children's sexuality, in these terms, if we ourselves are positive about it. This is obviously not enough by itself.

Parents also need very clear guidelines, as to what they can actually do and we know from experience in other areas that if highly motivated individuals are taught procedures, they pick these up and use them extremely quickly and effectively, and parents are certainly among the most highly motivated of all.

There are several ways in which these guidelines can be taught. Firstly with the aid of written material - there is some about - The Society of ~~Crippled Children~~, The Spastic Society have produced an excellent leaflet. A.S.B.A. have also produced a booklet. S.P.O.D. which has helped in the production of these, has leaflets of its own. These, among other information, should be given free and unsolicited to every parent of every affected child, soon after a diagnosis has been made, and we should encourage other organisations associated with handicapped children to produce their own material.

As well as written material, there should be a ready availability of certain necessary factual information, about subjects such as genetic counselling, puberty and masturbation. Parents are given genetic counselling if they themselves wish to have another child, but they are usually told that no genetic counselling can be offered about the child, until that child determines whom they wish to marry.

I think this is unfair for although no valid predict can be made about future generations on the basis of one parent, we do know that there are many disabilities that children suffer from such as cerebral palsy, or accidental damage that is not transmitted and many parents would be relieved of unnecessary anxiety if they had this information.

The work of Dr. Katherine Dalton on the age of menarche and the onset of puberty has shown that girls with many forms of handicap often menstruate earlier than able-bodied sisters; this is particularly important in spina bifida in which periods occur as early as eight, or nine sometimes even earlier. Boys similarly develop precociously and parents need to be ready to cope with these possibly very unexpected events. Research has also given us much more knowledge of the possible sexual capacities of individuals with cerebral palsy, spina bifida and spinal cord lesion and this knowledge should also be made available to parents.

I have already spoken about masturbation and some of the problems involved, but there are also very positive measures that parents can be helped with. The headmistress of a school for severely sub-normal in North London has been coping with the problem in a much more positive way. She has managed to help the staff not to get upset at the activity and suggest that the boy continues in the toilet, and returns to the class when he has finished. When he does return he is not reprimanded in anyway but is welcomed back.

Now this is an extraordinarily big step forward, for the severely sub-normal and yet it is relatively simple. I say relatively simple advisedly, because although it may take weeks or months before the lesson is actually learnt, and a lot of abberent behaviour may have to be tolerated in the meantime, yet compared with toilet training or feeding, both of which we manage to teach to most mentally handicapped children, it is very simple indeed, and the load taken off parents' minds knowing that their child is not going to embarrass them in the supermarket, in the club, in front of the neighbours, is very great indeed.

Another useful tip is to teach all mentally handicapped youngsters over the age of six or eight to shake hands. Many of them, particularly those suffering from Down's syndrome, are extremely affectionate, but whereas a slobbering kiss by a three year old may be acceptable by many, the same sort of kiss from a teenager may be extremely embarrassing. Learning to shake hands is a big social step forwards. These are some of the positive ways parents can be helped to teach their own children and understand something of the reality of what is happening to them. The third thing that parents need in counselling, so that they can have an opportunity to look at their own feelings of anger, disappointment, grief, anxiety and be given an opportunity to express within a safe relationship, negative emotions that might shock or upset family or friends; and also have a chance to look as realistically as possible at the implications and possibilities for themselves, their families and their children.

Some people say that the family with a handicapped child is a handicapped family. This need not be so, if there are opportunities for the feelings of parents and child and siblings to be expressed, to be put into words and coped with as realistically as possible. The decision as to when the counselling happens must depend on the wishes and needs of the family concerned; but it is necessary for Doctors, Social Workers, and others seeing parents and child to ask when taking a history, or at any other time, if there are any sex problems, or anxiety about sexual matters. Only a very few parents may take advantage of asking for help at that particular moment, but they will know, (because the subject has been raised), that they have permission to ask for help if it is needed in the future. Counselling is also necessary within an educational context, so that parents can help their children to accept their own emergent sexuality. Many adult doctors and social workers and professionals seem to be afraid of initiating any discussions of sex problems, because of fear that they would not be competent to cope with them when raised. They therefore, need to know exactly what resources for counselling are available in their own area and be in touch with a qualified worker who can recommend advice, counselling, family therapy, group therapy and find the professionals to do the work.

It is also necessary to train more counsellors to do this work, and train all professionals to understand a little more of the sex problems of disablement and the anxieties of parents, and others such as teachers, and and care workers, who are looking after the handicapped.

It is also necessary for all professional workers at some stage to have an opportunity to look at their own feelings about the sexuality of the disabled; and if, indeed, everyone did have this opportunity at some stage in our training, we might more easily accept our own hang-ups, and thereby be possibly less damaging to our patients and clients.

Another area where help can be given is to encourage the provision of more sex education for all disabled children; as part of a general programme about relationships, and to explain to parents what is being 'done'. and give them the opportunity to be involved in, and understand the programme, so that they can talk more freely with their children at home.

Lastly we need more education of the general public, to help them understand that disabled people are people, with the same human needs as other people. That sex and sexuality is part of the human condition, and that the disabled want to love as well as be loved.

Parents will continue for many years to come, to have problems in coping with their children's sexuality, but instituting some of these measures, may help to mitigate some of the problems.

SEXUALITY AND THE HANDICAPPED

David D. Stock*

The issue of sexuality in rehabilitation has been widely neglected because patients and professionals alike have found it a topic with which they are ill at ease. Beginning in the mid Sixties, the area of human sexuality emerged as a legitimate and increasingly important concern of rehabilitation professionals.

Even though we might think that times and attitudes are changing, as witnessed by what we read, sexuality remains a crucial problem for a sizeable percentage of people and it is more of a problem for people who are handicapped and who have lost the physical abilities necessary for some aspects of sexual functioning. I suggest that there continues to be no area of human functioning so fraught with superstitions and misconceptions, with warped thinking and prudishness, and with anxiety and guilt. Sexuality remains such a taboo topic that even married couples cannot discuss it openly and frankly.

If we search back into our own experiences, we find that: just yesterday, we were being taught such things as it is not right to talk about our sexuality; sex is only right in marriage; sex comes naturally, we will know what to do when the time comes. Just yesterday, we were being taught that the male is the aggressive partner in sex and the female passive, the male will know what to do because he has "sown his wild oats" and learned from those experiences, and the female will not only not find sex pleasurable, she will only tolerate it for the sake of her husband. Just yesterday, we were being taught that sex is solely for reproduction, that anything but heterosexual sex is pathological and any form of sexual experience besides penile-vaginal intercourse is perverted, and on and on.

With this overload of conflicting information, it is no wonder that sexual functioning has been so neglected in rehabilitation of the handicapped, when neither client nor professional can talk about it openly, comfortably, and knowledgeably.

As we look critically into our practice setting, and as we examine our daily practice, we see our limitations and uncomfortableness with the area of sexuality and the handicapped.

We manage to maintain a distance barrier in this important area of human functioning. We brush off the patient and say, "Oh, you shouldn't be concerned about that now!" We give the handicapped person confusing non-verbal responses that can't be interpreted. We develop a selective hearing loss as sensitive cues are given that the handicapped person has a concern in this area. We give a few statistics, make every effort to avoid emotional content, and call it sexual counseling - this seems to satisfy the requirement. And, institutional and hospital administrations give double messages to staff interested in providing services in this area.

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What then are the consequences of this state of affairs as we view the handicapped person and his sexual concerns?

The handicapped person can very easily and very early in the rehabilitation process find reasons from staff to discount himself as a sexual person. Rationalizing away sexual potential is the result since the handicapped person is given a combination of no information, conflicting information, or misinformation.

The handicapped person's mate, partner, significant other, abandons or unnecessarily limits the sexual role. This is a loss of great magnitude and is accompanied by considerable enduring emotional upheaval. Many times the individual cannot even discuss the problems with his or her partner and it remains a silent and smoldering issue.

The handicapped person and his/her significant other usually find other ways to express unattended sexual concerns. We can see this in innumerable complications in the marital relationship (economics, child rearing, lack of compromising over major and minor decisions). For the hospitalized person, the unattended sexual concerns may become visable through conflicts over visiting hours, refusal to go on a weekend pass, and delays in planning discharge. By avoiding these actions or activities, the potential sexual conflict is avoided.

Again, for the handicapped person with a recent injury, sexual concerns may be masked in periods of prolonged depression and a lack of desire to engage in daily rehabilitation and self care routines.

Finally, the institutional attitude and/or attitude of the staff interacting with the handicapped person is a very important consideration.

Having taken a brief review of what seems to be the current state of practice in many areas and rehabilitation settings, and what the consequences of this level of practice is to the handicapped person and his significant other, the remainder of the paper will specifically address some of the major concerns of persons with spinal cord injury, some ways to equip ourselves to handle sexual concerns, some precautions, and finally, suggested areas to be covered in discussing sexuality with handicapped persons.

SPECIFIC SEXUAL CONCERNS OF SPINAL CORD INJURED PERSONS

It can almost go without saying that unattended sexual concerns take an enormous toll on the individual and family. Without doubt, sexual problems create disharmony and conflict in marital relations and in single persons' relations as well.

Frequently, the question is asked, when do sexual concerns begin? In SCI, sexual concerns may begin shortly after hospital admission. Frequently, wives of SCI men are told by their partners to divorce them and find someone who can meet their needs. This is usually a concern that is begging for more exploration and evaluation. Without timely intervention of counseling in this delicate area, meaningful communication stops, open communication and the relationship disintegrate.

Issues of relationship are also very important for the single person who may wonder whether he or she will be acceptable to a boyfirend or girl-friend, or whether marriage can be considered. These issues all seem to relate to one's self image, they therefore have some sexual foundation and must be dealt with very early. It is safe to say that sexual concerns usually begin very early - and that there is no one barometer to read to plan timely assistance.

The patient's concerns about his sexuality may be manifested in a fixated response to a particular part of his medical problem; for example, a patient may ask endless questions about the urinary device. It is essential to determine whether the real concern is sexual - how will the catheter interfere with my sexual activities? - or, is the catheter and its permanence, irritation, etc., the problem? - or, is there a combination of both these issues?

Sometimes, sexual concerns are disguised in a fairly general depression that is labeled as a reaction to illness or injury. It is important to determine whether the depression is rooted in sexual concerns, and can they be dealt with in a timely fashion. Misunderstanding and misinformation begin at a very basic level.

Sexual concerns frequently seem to be hidden and disguised as the patient approaches discharge or a weekend pass. Since he and his significant other have not discussed sexuality, they may fear or be reluctant to go home, therefore avoiding a sexual confrontation. Many times, significant others will ask whether they should sleep in the same bed with their partner, thinking that he or she is still a patient and just too fragile. Again, remember that misunderstandings and misinterpretations are very basic.

Finally, a host of sexual concerns and problems are unmasked following discharge and when the handicapped person and his significant other have the least access to professional assistance:

--they may avoid sexual intimacy because they don't know what to expect
--they may find old roles - male aggressor, female passive, don't work
--they may find experience very frustrating and unsatisfying in comparison to former performance, and recollection of feelings about sexual experience and expectation
--they may find that if total sexual experience was penile-vaginal, missionary position, difficult adjustments are ahead
--they may find that over time, s.o. becomes less of lover and more of nurse or caretaker.

EQUIPPING OURSELVES TO HANDLE SEXUAL CONCERNS

Because all aspects of the patient-client handicapped person's psycho-social functioning are dynamic and interrelated, it seems to hold that sexual counseling should be done within the context of general counseling and that to assign the sexual component to a special therapist is in most cases an unnatural separation. This does not preclude the use of consultants who can offer special techniques. Built on this basic premise, how do we equip ourselves to handle sexual concerns?

We must prepare ourselves in two ways: personally and professionally. In personally preparing ourselves, we must exmaine our own attitudes and values and come to accept our sexuality, for in a counseling situation we are not only therapist to client, but one sexual human being to another sexual human being. We must be able to talk about sex openly and comfortably.

How does one become open and comfortable, if he is not already? At our facility (The Institution for Rehabilitation and Research, Houston, Texas), in 1972 we adapted and developed a three-day program (Sexual Attitude Reassessment Workshops - SAR) which reduces the misgivings, mythology, and apprehension surrounding the topic of sexual functioning and aids participants in reassessing their sexual attitudes and assisting them in becoming more comfortable with their own sexuality both personally and professionally. This program, which is appropriate for both client and professional, aims at opening up communications between the client and his partner and between the client and whoever may do sexual counseling with him.

Two kinds of techniques are employed in this program. One is the presentation of a wide array of audiovisual material dealing with sexual mythologies and a variety of sexual activities. The other is the use of small group discussions at strategic points throughout the workshop.

We believe that crucial aspect of the program to be the small group. It provides the safe, protective conditions under which additional change can take place. Here the participants work with facilitators to engage in self-examination and sharing of personal feelings elicited by the audiovisual presentations. We believe the real change occurs here as the individual comes face to face with his own attitudes, beliefs, blind spots, hangups, as he shares his feelings with the group and as he listens to the views and opinions of others.

By way of indicating the importance of this kind of program to professionals, a quote from Dr. Ted Cole, who originated a similar workshop, seems appropriate:

> "It is difficult for many people to deal directly with explicit sexuality. However, this is important for us to be able to do if we are going to be helpful to patients and clients. We can learn about our effect on disabled people by looking at our own attitudes. One's attitudes are often apparent to others even though a conscious effort is made to hide them. If this is the case, it is necessary to ask whether our attitudes are enabling or prohibitive. By our attitudes and actions, do we communicate messages which enable the disabled to grow, adjust, and rehabilitate themselves? Or do our attitudes and actions forbid certain activities and discourage a desirable outcome, in effect, adding a new disability to the pre-existing one?"

There is reason to believe that for many disabled persons, the sexual handicap may not be so much a matter of limitation due to physical incapacity as to limitations due to mental and emotional barriers - thoughts, ideas and fears that prevent one from free and uninhibited experimentation with a variety of sexual techniques. We feel that a couple's chances for sexual gratification are as great as their freedom to explore, to discover ways that are mutually satisfying. We assume that everyone has the capability for sexual enjoyment if attitudinal barriers are removed.

Once the counselor is able to handle explicit sexuality and language, has identified where he stands sexually, the next step is to equip himself with effective therapeutic techniques and a thorough knowledge of human sexuality and sexual relationships. Scores of continuing education workshops and seminars are being offered, and there are countless books on human sexuality. The goal is to incorporate techniques which fit your style and the needs of your clients. However, I am convinced that if the counselor is not comfortable with his own sexuality and sexuality in general, the most sophisticated technique will not prevent him from communicating his discomfort to his patients.

Even though a counselor has equipped himself to do sexual counseling, there can still be some blind spots. A number of cautions have been offered by George Holhmann, a psychologist in the United States Veterans Administration System. Since sex is a personal matter and a sensitive topic for clients and often for the therapist, Holhmann suggests we consider the following precautions:

1. Don't get people into trouble with their God or their morality. Many people have strong religious convictions that would lead to anxiety and guilt, if certain sexual activities were practiced.

2. Don't hang your morality on the patient. You have a right to your own convictions in this regard, but you do not have the right to force them on someone else.

3. Don't force the patient to talk about sex - timing is important.

4. Don't threaten the patient with your own sexuality. Male counselors, for example, may intimidate the patient by bragging about their own sexual exploits, while female counselors may be seductive toward a male patient when they feel there is not a threat.

5. Don't make sex an all or none experience. That is, don't assume that sexual functions must involve genital sex and orgasm.

6. Don't assume that once sexuality has been discussed, it is forever resolved for the patient. Conditions may change and the topic should be left open.

7. Don't assume that there is only one way to convey sexual information. It may be best conveyed in a serious way with some patients, and with others in a jocular fashion. Some patients can better accept information when it comes from other patients.

8. Don't expect too much from spouses in their ability to change roles. Where the spouse has to carry out anesthetic, personal care activities with the patient, it may be too much to expect that he/she can play the role of lover. In these instances, we may encourage the use of an attendant to carry out personal care functions.

9. Don't forget that all relationships, and, in particular, that most intensive relationship - marriage - is a matter of compromise. This is to say, that a couple needs to work out patterns and activities that are mutually satisfying.

A precaution from my own experience is the following: don't confuse the provisions of a few pieces of information as sexual counseling. Keeping these cautions in mind as you provide sexual counseling may be very helpful to you.

SUGGESTED AREAS TO BE COVERED IN A SEXUAL INTERVIEW:

1. Help the handicapped person and his/her significant other explore alternative ways to give and receive satisfaction. For the female handicapped person, it might mean more communication about what feels good. For the male handicapped person, it might mean communication to deemphasize the erect penis. For the couple, it might mean other things besides pe-

nile-vaginal intercourse.

2. Help the handicapped person and his/her significant other consider what role changes are required. They might need to alter passive-aggressor role identity. They might need to understand and explore what feelings and values are linked to definitions of feminity and masculinity.

3. Help the handicapped person and the significant other to understand that each is responsible for his/her sexuality.

4. Help the handicapped person and the significant other to understand that either person can initiate sex.

5. Help the handicapped person and his/her significant other to deal with the lover-caretaker conflict.

6. Help the handicapped person and the significant other strive to use open, honest communication.

CONCLUSIONS:

Unattended sexual concerns of disabled persons and their partners cause a multitude of other problems. We have a personal and professional obligation to equip ourselves with self-awareness and acceptance of our sexuality, and to add a repertoire of sexual counseling skills. We need more than our own personal experiences and private opinions to find the best answers to sexual problems. Health professionals who have useful information concerning sexual problems often lack the ability or comfort to use the information they have. Sexual functioning is an important part of a handicapped person's total functioning and must become part of our concerns as we assist the person in his rehabilitation and adjustment.

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A social psychological interpretation of my 'disabled' relationships.

John Stewart*

ABSTRACT

This is essentially an autobiographical paper in which it is attempted to link my own experience of the effects of disability to the concepts of social phychology. The history of changes in my psychological balance and their influence on my social relationships, especially the closest of these, with my wife, will be described, and some conclusions on the bearing of the experience of disability on the social unit of the family will be attempted. Above all it will be suggested that only those with deeply personal experience can speak authoritatively of its effects. For something as traumatic as disability must have an effect on relationships. I have been relatively fortunate, in that I have survived the experience and made of it a constructive rather than a destructive incident. Throughout the paper I shall attempt to extend the optimism to those who have not perhaps achieved my level of integration , and encourage them to attempt to emulate my achievement. There is nothing inherently disintegrating about disability, though this of necessity requires the support and encouragement of those closest to the 'victim', which I fortunately have had. To those involved in this supportive role, I would say, be patient and understanding. Remember that adjustment to some sometimes severe deprivation takes time, usually initially about two years. If adjustment has not been effected by the end of this period, then perhaps is the time to shout 'help', but especially the experience of paralysis has been associated with grief, which only dies with the passing of time.

Eight years ago I fell 38ft from a hotel window. Indeed as I write I am two days away from my 8th anniversary of my 'rebirth' day, when I entered this strange world of the disabled. I say 'fell' because I have been assured by doctors that if I had consciously jumped I would almost certainly have died, and diminished the 5% chance of survival with which I was admitted to hospital. As my presence here today demonstrates, I clung on to this diminutive chance, and perhaps because I ate my porridge when I was young, perhaps because I had been married only two months previously (and even then my wife's cooking wasn't that bad), perhaps because only the good die young, and I scarcely qualify, I recovered to my

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present condition, where the only things I can't do are walk, hear anything through my right ear, and use my right arm as efficiently as my left. I never was very good at displaying humility and increasingly this has not changed as again is evidenced by my presence in this position today.

After my accident I was admitted to the intensive care unit of the Royal Sussex Hospital at Brighton, to the staff of which I owe my life, for they knew what to do, and proceeded with it without fuss or confusion. After a few weeks there I transfered to Broomfield Hospital at Chelmsford, where my wife,Judy, wasthen a ward sister. Not because of this I was again very well cared for. Responding to pressure of 'experts' I transfered from Broomfield to Stoke Mandeville. I shall explain why this was perhaps the worst move of my life if anyone would like to ask me after this talk.

After a few months I was discharged from Stoke, without a job arranged, or anywhere adapted for me to live in. There followed two years of near despair, when we lived on sickness benefit of £7:90 a week, plus my wife's earnings as a part-time nurse. I survived and emerged from a period of acute depression, and at last after a not inconsiderable effort on my part, returned to work. Against some opposition I regained my former employment, and have been in that post since I973. This return was central to my rehabilitation, which I consider is now as complete as it can be.

That is sufficient initial autobiography though I shall be very happy to expand my comments, or describe my experiences, if any of you wish to ask questions after this talk.

Allow me now to present a more academic approach to my situation. Let me quote from 'Social Physchology' by Thouless, published in I925: in defining social physchology he wrote ' an ill defined but important study lying between normal adult physchology on the one hand, and social on the other. Its object is to provide a science of man in his social relations by studying the elements in normal adult physchology which affect the formation of social groups and the interaction between individuals in such groups'. You will note that the word' normal' occurs twice in this definition, but this is just the aspiration of many of us disabled, to be accepted as normal as possible, however this disputed term is defined.

My accident has certainly had an effect on my physchological balance, which in turn has affected my social relationships especially the closest of these, that with my wife. Before my accident I was the dominant, sometimes domineering partner in our marriage. I was almost entirely self-sufficient, self confident. Indeed my wife has reminded me that once I maintained 'nothing will ever happen to me', and then this happened. Immediately, probably inevitably, I became much more dependent. Very fortunately Judy, with her training and experience as a nurse, was able to accept this metamorphosis,and became my defence against the world 'til I was ready to return. This was my period of maximum dependency, from which I slowly emerged until I went back to work. During these years Judy gave me the support I required to ensure initally my survival, subsequently my way bac k to the world of work. I shall never cease to be grateful to her for this faithful upholding.

But return I did, and I was delighted and astounded to find that I was still attractive to women, despite-in some cases I suspect, because of - my wheelchair. It gives an impression of safety, as well as justification for their response. As my former confidence, at times bombastiness, was restored, I progressively reduced my dependence on Judy..As this occurred our societal relationship was inevitably affected, and emotionally we have grown apart. We are still very good friends, but perhaps because of the dependence I have described, we are scarcely now good lovers.

Very fortunately for me (and the Director of RADAR has recently reminded me how fortunate I am in considering this possibility, in that many of us the disabled could not envisage separation from their supportive partners) I have discovered someone else who will accept me- warts and wheelchair an' all. There is some difficulty- is there not always- in that she is married too, with a far less understanding partner than the one I am blessed with, but eventually the situation may sort itself out. But of one aspect I am certain, unless I know that Judy will be happy away from me, I shall never leave her. Ours is a very strange combination; if we do separate it will be as close friends with no bitterness. Friends of mine have judged ' if you have something well going for you, hold on to it' but I am not sure this is the right attitude- it smacks of selfishness. In my case I am confident that inter-personally things are 'not going well' for us. Perhaps our relationship c ould be patched up, but would this be justified? 'Normally' the situation would be accepted, and in that we seek normality it is unjustifiable that I should add to the responsibilities and pressures of marriage the penance of my disability. She did not marry me as disabled. It may be that if it were not for my accident our marriage would not have survived as it has. In that she has cared for me throughout my 'chrysalis' stage, and should I expect her- or require her- to wield a butterfly net? Especially since there is someone else who is prepared to, ready too to accept me with my disability

So you see that my psychological variance has significantly affected my marital sociological relationship. The 'interaction between individuals' in our nuclear social group has clearly been influenced by my fall. But the flow is not unidirectional. While changes in my psychological structure effect my societal relationships, variations in the latter have their influence on my psychological balance. Sociology and psychology have their contribution to make in analysing my situation , but it is in the combining science of social psychology that adequate interpretation is found. Only by a combination of these inextricably interwoven disciplines can a rational solution be found to my, and many others,problems. I well remember a letter I received from one of our, severely spastic members in which he claimed- unfortunately justifiably, that this was perhaps the first occasion in which a spastic had been named as the'correspondent' in a divorce case. But why not? Why should not more of we, the formally - and I am tempted to claim- formerly disabledbe involved in a process which is unfortunately too common in our modern society-divorce-especially since our demands on the marital status tend to be somewhat excessive. Why should not we, as distinct from any other goups, make use of this 'escape route' from a perhaps intolerable situation. Why should we be considered different, just because we are! I wish to emphasise, as a social psychologist, that whatever we demand as disabled members of society, we are more than prepared to balance with our acceptance of duty, which we owe to that society. I shall be prepared to comment on any remarks you might like to make in response to this aspect of my presentation.

With regard to my extra-marital relationships, there are two areas I wish to exmaine with you. The first is the reaction of my parents-in-law, and theirs to me. Before my accident there was a certain distance between us, perhaps because of my famous bombastiness, but later this developed into a relationships of affection and trust as I realised that even I could be dependent! Mum and Jack have responded superbly to the fact and implications of my disablement; they give me the assistance I need, without offering help when it is not needed. In addition, Jack has been very faithful in caring for my somewhat extensive garden, which is a duty I am unable-or unwilling-to perform myself. As an extension to this, I believe I am much more acceptable to my mother-in-law than is her other son-in-law and I cannot divorce this preference from the existence of my disability, and the effects of my accident on my personality. Before I had little time and respect for them but since I have come to value them far more, not just as willing pushers and gardeners, but as individuals with a distinct and worthwhile contribution to make to society. I think they will continue to be my friends, whatever happens to my marriage.

This is another example of the influence the alterations in the psychology of my personality, caused by my accident has had on my societal relationships. Social psychology provides a framework for explanation that is not available when the two constituent disciplines are considered separately.

Now for my other friendships. Before my fall, I had a few close friends, who have accepted my disability superbly. They are still my friends, and my accident if anything has drawn us closer together, though a combination of their geographical remoteness and my (relative) difficulty in travelling unfortunately reduces the frequency of our meeting. My oldest friend (in years of friendship) has emigrated with his wife to Canada. I am seriously tempted to join him, since I visited the country a couple of years ago and found it exciting and interesting. In most ways their provision for the disabled makes ours look rather inadequate. Again I'll expand this theme if anyone wishes to ask me after this talk. For now, back to the subject. As I maintained a few moments ago, my close friends have remained faithful. Perhaps everyone should have an experience, though not so drastic, to discover who his true friends are. But an added bonus to my disablement is the number of friends I have made since my accident in the sphere of disability. People I almost certainly would not have met if I were not in a wheelchair. This seems to be veering towards a sociological explanation, but the implications of psychology cannot be ignored. In much more than a physical sense, disability is a great leveller. Class, education, occupation are forgotten as two disabled people meet. Whatever the cause of the disablement- whether it is traumatic or congenital-, and whatever the severity, its presence provides a bond of experience which far outweighs the aforementioned 'accidents of birth'. The psychological balance of the individual is also affected: the proud become more humble,and the meek experience an agrandisement as a result of coping with their handicap.: So among the disabled there is a sense of equality, a levelling, which facilitates the formation of social groups, which contain a meaningful and well justified interdependence. There is a respect which is not reliant on the customary social factors for its creation.rather it is the direct result of the experiential background of the constituent indviduals.

Here again we observe sociology and psychology intertwined, and it is only in the discipline of social psychology that an adequate solution to the problems of disablement can be found .

DISABLED FAMILIES

*Eda Topliss

ABSTRACT:

The impact of a disabled member on the family is examined on the basis of several studies of disabled people, and a survey of over a thousand physically disabled individuals under retirement age living in private households.
First of all the financial consequences for families are considered and related to the position in the family of the disabled individual (i.e. whether husband, wife, or child).
Secondly the effect of disablement on family relationships is discussed. Particular attention is given to the evidence for marital strains resulting from disablement of one partner, and how these are reflected in the divorce rates among the survey population examined.
Finally the lack of supporting services for families with a disabled member is noted for the effect this has on the opportunities for integration into the community of the handicapped individual and his family.

Although the precise impact of disablement on family life depends on the position within the family of the disabled person, a growing body of literature suggests that whether it is a handicapped husband, or wife, or child, who is affected, disablement has an effect on the relationships and opportunities of the family as a whole.

DISABILITY AND FAMILY FINANCES

One area in which disablement makes its impact is that of family finance. Even when disablement does not involve complete loss of employment, it often results in a marked reduction of earning capacity. (1) In the survey of over a thousand disabled people under retirement age in Southampton, it was found that although 42% of those over school leaving age were in employment, still 85% of all respondents were in households with total income which was below the then average adult male earnings of £40. per week. Half the households had an income at or below the poverty line - defined as the level of standard supplementary benefit payments. The majority of disabled people in the survey, therefore, did not

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have the level of income to meet any extra expenses of disablement, with consequent deprivation, experienced in one way or another by all members of the households.

Families with a disabled housewife appear to suffer financially almost as much as those where the breadwinner is disabled; whereas 85% of all the families with a disabled member had an income below £40 per week, 79% of those households where the disabled person was the housewife had an income below £40 per week. It was not that, in most cases, the husband had given up work to care for his disabled wife, but many husbands spoke of being unable to do overtime because they were needed at home, and some considered their domestic burdens had reduced their promotion opportunities. Above all, the disabled wives themselves were far less likely to be in paid employment than were able-bodied wives of the same age group, and their families lacked the second income that is so common in most marriages, except for the years when the children are very young.

The Housewives' Non-Contributory Invalidity pension, however, is not payable to disabled married women who are unable to take up paid employment outside the home unless they are also quite unable to cope with normal housekeeping duties. In other words, eligibility for the housewife's pension is based on far more stringent definitions of disability than is the case with men and single women, yet the impact of a disabled wife on family income and life seems to be every bit as severe as when the disabled person is the husband.

On the whole, a handicapped child in a family does not greatly affect the family's income level, at least at first, since most mothers with young children do not work and accept a period of relatively low family income. Once a child is older, however, the majority of mothers return to at least part-time paid employment. It is at this stage that the demands of a handicapped child are likely to be felt as a restriction of the mother's ability to take up employment.

There seems little doubt that for the vast majority of handicapped people, their lives and those of their families are narrower and more circumscribed than their disabilities alone make inevitable, because they lack the financial resources to make compensatory provision. It is not, however, suggested that money difficulties are the principle consequence of disability in the family. It is merely that the financial consequences can be quantified and objectively measured. The deeper emotional impact of disability, both on the individual himself and on his family, is much more difficult to assess.

FAMILY RELATIONSHIPS

There are some subjective accounts of the awareness of disability, written by individuals incapacitated by various diseases (2). There have also been attempts by sociologists and psychologists to describe the process of adapting to disability (3). Despite the fact that all these accounts of reactions to disability stress the significance for the dis-

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abled individual of how other people regard him, very little work has been done on the emotional impact of disability not only on the individual who is disabled, but also on the members of his family and relationships between them.

From studies which have been completed, it appears that disablement occurring in a spouse after marriage requires very considerable adjustment of marital roles. One survey of thirty-six married women who had become disabled found that they expressed far more satisfaction with the companionship they shared with their husbands than did their respective husbands (4). For the disabled wives, the fact that their husbands had to spend more time at home looking after them only emphasized the home as a focal point in both their lives and was regarded as an increase in companionship. The husbands, however, still wanted wives who could accompany them on activities outside the home, and therefore registered dissatisfaction with the level of companionship remaining in marriage after disability in the wife. Those husbands who were tolerably satisfied with their lives despite the severe disability of their wives, were found to derive considerable satisfaction from their work, or from social activities undertaken independently of their wives. This study indicates that satisfaction with a marriage may be greatly reduced for an able-bodied husband having a disabled wife, though the same might not necessarily be true for an able-bodied wife having a disabled husband, since for her his dependence would merely intensify her home-centred role. In her capacity as a mother, also, she has experience of caring for children at varying stages of dependence, from the totally dependent infant to the nearly independent adolescent, so that she has a ready-made model on which to base her care of her disabled husband, according to his degree of dependence.

A marriage would appear to be at greater risk if the wife becomes disabled than if the husband does; and the risk becomes greater still if the husband cannot find success and satisfaction in his work role to compensate for the loss of the active companionship which his disabled wife can no longer give. The fact that several husbands of disabled women included in the Southampton survey expressed the view that their need to spend a good deal of time looking after domestic matters had interferred with their job, suggests that for many husbands, dissatisfaction at the loss of the active companionship of their wives is aggravated by their feelings of lost job opportunities. This may explain the high rate of breakdown of marriage among disabled women in the survey - 16% of them were divorced or separated, compared with a national divorce rate of 9%. On the other hand, among the disabled men in the survey, only 4% were divorced or separated. The vulnerability of marriages where the wife becomes disabled was noted by Sainsbury (5) but Blaxter's numerically small study indicated the reverse (6).

One area of companionship about which there has been increased concern lately is that of sexual relationships. In 1973, the National Fund for Research into Crippling Diseases set up a committee to enquire into the sexual implications and aspects of disability. According to the committee's report (7), all severely handicapped people experienced sexual problems associated with their disability, and most disabled people, whatever the level of their handicap, at some time suffered some sexual impediment associated with their disability. Yet only about a quarter of the disabled people included in the survey were impotent or partially impotent (in women this was defined as lack of clitoral/vaginal sensitivity). A further group were found to experience difficulty in sexual relations because certain postures were uncomfortable or impossible, yet practically no one had received any advice on how to overcome the difficulties. The majority of sexual problems, however, seemed to be rooted in the tendency of the general public to write off the disabled as sexual beings.

Such an attitude militates against the development of facilities and services to encourage the sexual development of disabled young people. The severely disabled, heavily dependent on others to organize their environment and social activities, find the opportunities to form friendships leading to expressions of sexual affection, frustrated by lack of privacy. The lesser disabled, who achieve greater independence to mix fairly freely, are likely to form friendships with able-bodied young people, if only because they will form the majority of their contacts. But when it comes to love, they may find the modern emphasis on physical attractiveness as a basis for sexual relations militates against the acceptance as a sexual partner of anyone less than physically perfect. So far, however, there is little if any counselling available to disabled young people to help them cope with their awakening sexuality in the context of an unhelpful, even unsympathetic, society.

For someone who becomes disabled after marriage, the impact of disability on the couple's sexual relationship may be far more severe than the actual degree of functional loss makes inevitable. Both the disabled person and the spouse will enter the new situation with the legacy of their able-bodied past and the norms which link sexual relations with physical attractiveness. The problems are likely to be greater when the disability is the result of sudden trauma. In a slowly progressing disease, the couple have time to adjust their outlook gradually and to adapt their practices in order to give sexual expression to their affection in a manner compatible with the declining physical capacities of the disabled person. The couple must almost always work out this adjustment for themselves, though, as it is extremely rare for any counselling to be offered.

The ability to give such counselling is sadly lacking: for most medical students there is very little teaching on rehabilitation of the disabled, and what is taught tends to be limited to the rehabilitation of a disabled person as far as personal care and hygiene are concerned. Rehabilitation for the activities of employment is undertaken in some hospital settings, but rehabilitation for social life, including personal relationships and sex, is virtually absent from the teaching of medical students. It is not surprising, therefore, if doctors feel themselves unable to give counsel in the sexual problems of disabled people. Unfortunately no other body of caring professionals is any better trained than the doctors to give such help.

Where the disabled member of the family is a child, not only is the parent/child relationship likely to be affected, which most people can readily understand, but also the relationship between the spouses. Studies of families with handicapped children (8) have documented that caring for a handicapped child absorbs even more of the mother's time and energy than does the care of an able-bodied infant, and the dependence of the handicapped child lasts throughout its life. These studies also indicate that mothers with handicapped children went out with their husbands less often, on average, than did mothers of able-bodied children of the same age. One can assume, therefore, that the degree of active companionship a mother with a handicapped child can offer her husband is less than the couple would otherwise share. In the case of disabled wives, it appears that husbands do not find home bound companionship an adequate substitute for the companionship of their wives in outside activities. It may well be that even if fathers of handicapped children share a good deal of the care of the child, such home bound companionship with their wives will not compensate for the loss of more active forms of companionship, and marital dissatisfaction and stress would result.

Despite the strain of caring for a handicapped child, however, most families do give such care in their own homes. With a severely disabled child, the difficulties of caring increase with time: the older and heavier the disabled child, the more physically demanding becomes the caring role. Ultimately the ageing parent is unable to continue giving such care, and a residential placement for the disabled person becomes the only practical solution. It is the anticipation of this time that adds to the distress of parents with a handicapped child, and, indeed, to the distress of the disabled person himself as he watches his parents ageing. In Southampton it was found that while only 28 respondants out of over a thousand disabled people had ever considered the possibility of residential care, in six of these cases the respondent was a parent, answering on behalf of a severely handicapped young child, who envisaged with dread that a time would come when the disabled son or daughter would have to go into residential care.

It is clear, from the ages of the majority of unmarried disabled people who enter residential care, that parents go on looking after their disabled children long after the parents have reached an age when they themselves could do with some help. This means that there are a number of extremely vulnerable households where elderly parents are caring for disabled off-spring, and where any moment there could be a complete breakdown of care due to the illness or death of the parent. This was indeed the picture revealed in Southampton when emergency admissions of disabled people to hospital were examined (9). The admission was freqnently necessitated not by illness of the person admitted, but by a breakdown of their care system due to the collapse of an elderly parent.

SUPPORT FOR FAMILIES WITH A DISABLED MEMBER

At present the only real choice for a disabled person is between family care, for the most part unsupported by outside help or services, and institutional care. Although in theory the personal social services can provide a good deal of assistance to disabled people living with their families in the community, in practice the help received is minimal. The Home Help Service, for example, is concentrated on the elderly, many of whom, of course, will be incapacitated to varying degrees, and less than 7% of calls are to families looking after a disabled member under retirement age. Again, it is only a minority of disabled people living in the community who , through the Social Services, receive home adaptations, attend clubs or occupational centres, or are given holidays or offered transport to and from leisure activities (10).

This undoubtedly means that the lives of disabled people and their families are often very restricted, due to a combination of limited finance, restricted mobility in homes which are often unsuited to the accommodation of disabled individuals, and lack of energy after the necessary tasks of care have been performed, to arrange leisure and social activities outside the home.

Residential care, by contrast, offers the convenience of purpose built, or at least extensively adapted, premises especially planned for the greatest mobility and independence of disabled occupants, with staff to give the necessary care and attention. Despite these advantages, it seems quite clear that few disabled people, however seriously handicapped, choose to enter residential care. They enter it, if at all, only when home care has completely broken down, or become an insupportable burden for caring relatives. Institutional care is seen by most disabled people as a last resort and not as a preferable alternative to living at home, however unsuitable the dwelling may be which is called home, and however restricted to four walls may be the life of the disabled person.

Although life in a private household may thus be seen as the choice made by the majority of even severely disabled individuals and their families, the meagre level of support available to such families makes it quite clear that the enormous burden of care means the restrictions of disablement affect the family unit as a whole. These restrictions can be so numerous as to result in the disabled person and his family living in the community, but being unable to be part of it in any meaningful way. We need to be very clear what we mean by "integration". If, for example, we mean that by caring for a very disabled person in a private household, that person will be more integrated into his family than if he were to be in residential care, that is likely to be accepted as true. If, however, we mean he will be more integrated into the community in the sense of participating in such community activities as local bingo clubs, or theatre going, evening classes, or employment, it is quite possible that the better physical facilities of residential care could promote such activities rather more than the family is able to do whilst absorbed in, and often exhausted by, giving the necessary basic care. There are, in short, several dimensions of integration, and for a disabled person to live in a private household rather than a good residential unit may promote one aspect of integration (with the family) but at the expense of another.

It may well be that most disabled people, and their families, are willing to sacrifice other forms of integration in order to retain the integration of the disabled individual into his family. But we should not, as a society, pretend that this is the same as integration into the community - or even that, with the level of social support currently available to the families caring for a disabled member, it is compatible with integration into the community. It is perhaps better to be seen as the willing acceptance by society of the inclination of disabled individuals and their families to put family unity before community involvement. If it leads to segregated families, rather than a segregated individual, society is able to ease its conscience by claiming it is what disabled people want.

The danger of this self-deception on the part of society is that it encourages the complacent view that, as long as disabled people are living in private households and not in institutional care, a desirable state of "integration" has been achieved. There is then little incentive to improve the community facilities for families caring for a disabled member, or to develop imaginatively the range and quality of residential care provision, so as to afford disabled people a meaningful choice of pattern of life.

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THE DISABLED ELDERLY IN A CHANGING WORLD

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Abstract

The physical and mental health of people aged 65 and above is usually very good. They are fully able to take care of themselves, even if they are in some instances denied the right to work, at least in their former jobs. Disease and ill health are the exception rather than the rule in this age-group, and should be regarded as such, the aim being to re-establish independence. The health protection services and activities developed for the community in general will usually cover the needs of those aged 65 and over. Since family and local community influences are the strongest determinants in health protection, then clearly information and education can exercise an important influence on the cultural attitudes of the population. From this point of view especially it would appear to be very important never to refer to the elderly as a "problem" within society.

INTRODUCTION

There is evidence that within the group called the elderly there are many who will be faced with growing difficulties in coping with the problems of everyday life and changing environment. The planning for the health care of such groups is also made more difficult by a lack of information as to who really are the elderly, who constitute this group in a given country, what their problems are, and what, if any, are their special health problems.

It is equally important to emphasize that in a demographic sense the cause of the aging of populations is a complex one, but equally it should be recognized that any important and sustained decrease in fertility produces "ipso facto" an "aging" of the population. Consequently, the populations of developing countries which have a young structure will age if their fertility follows a generalized downward trend. Further, this process of aging of populations will be quicker than that which has already taken place in the industrialized countries. One must also add a second major factor, that is, reduction in mortality during the second half of life. It is reasonable to forecast a further aging of populations resulting from a combination of the two processes. A third phenomenon, that of the migration of young people out of, or the elderly into, certain regions or localities, may result in still greater aging of some populations than the two previous factors alone would produce.

Further, as suggested in The Determinants and Consequences of Population Trends (United Nations, 1973, p. 289)[1], there is a distinct difference between the concepts of individual aging and the aging of human populations. Both are concepts which have only recently received scientific attention. Individual aging emphasizes irreversible stages of the life span, the understanding of which is dependent on knowledge of the biological, sociological and psychological processes associated with growth, maturation and possible decline of the human organism within the context of physical, psychological and social environments.

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[1] The Determinants and Consequences of Population Trends: New Summary of findings on Interaction of Demographic, Economic and Social Factors, Volume 1. Department of Economic and Social Affairs, Population Studies, No.50. United Nations, New York, 1973.

The views expressed in this paper are those of the author and not necessarily those of the World Health Organization.

EXTENT OF THE PROBLEM

It is important that for issues of policy formulation planning, and in the development of new institutional responses to the aging populations of the world, demographic data be examined in terms of aggregate numbers as well as in regard to the proportions of the older populations, vis-a-vis other aging groups. For example, as seen in Table 1, the 60-and-over population while representing only 8.4% of the world's total in 1970 and 9.3% in the year 2000, in numbers represents 304 million and 581 million persons, respectively. This nearly doubling of the older age groups in 30 years has far greater implications than their percentages of the total populations would suggest. Between the years 1970 and 2000, for the world as a whole, all ages are expected to increase by 73%, the 60-and-over population will increase by 91% while the 80-and-over population will increase by 119% or almost half again as rapidly as the world's population of all ages (see Table 1).

For the more developed regions and countries, which have experienced a decline in birth rates, the proportions and numbers of the older population have increased steadily over the past decades. It is in these regions and countries that the greatest attention has been given to social policies and practices regarding the aging. It is also in these countries and regions that the greatest attention has been given to the increasing numbers of persons of extremely advanced age. As suggested in Table 2, the world in 1970 had 3.6 billion persons with slightly less than one-third being found in the more developed regions and slightly more than two-thirds in the less developed regions. Of the world's 304 million persons who were 60-and-over in 1970, about 50% were found in the more developed regions and another 5C% in the less developed regions, with a difference of slightly more than 2 million persons 60-and-over to be found in the more developed regions.

No region of the world can be described or defined as exclusively more developed or exclusively less developed. Within each are some areas which are more industrialized and economically more affluent than other areas which may be characterized as more agrarian and economically deprived. These terms, therefore, are used to suggest broad rather than specific differences in regard to economic development. For the 80-and-over population which numbered some 26 million in 1970, 61% were found in the more developed regions and 39% in the less developed regions. However, if one is to look to the year 2000, the 60-and-over population will be increasingly found in the less developed regions, that is 60%; and, for the 80-and-over population, nearly 46%. It is also of interest to note

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In the preparation of the demographic data in this section use has been made of material prepared by Professor Walter M. Beattie, Jr., Director, All-University Gerontology Center, Syracuse University, Syracuse, New York, U.S.A.

that for the world as a whole, there were some 26 million persons 80-and-over in 1970. By the year 2000, this same number of persons 80-and-over will be found in the less developed regions alone.

It should be noted that the proportion of persons 80-and-over within the 60-and-over population is increasing. For the world as a whole this group represents 8.7% of the 60 and over population, and by the year 2000 will represent 9.9%. This proportion within the older population is more pronounced for the more developed regions, 10.5% of those 60-and-over in 1970 and 13.3% by the year 2000. This is the age group which is most frail and vulnerable, and which may require the greatest range of specialized services and facilities.

The importance of identifying human populations by aggregate numbers as well as by proportions to understand the implications of aging is again illustrated by examining each of the major regions of the world. Table 3 identifies each region for the years 1970 and 2000 for the 60-and-over, and 80-and-over populations, and their proportionate changes between the years 1970 and 2000 as compared to all ages within those regions.

South Asia, which had the largest number of the world's population in 1970 (1.1 billion), will have an increase of more than 100% of this total by the year 2000. Although the 60-and-over population was only 4.9% in this region in 1970 and will represent only 6.1% by the year 2000, in numbers there were nearly 54 million persons 60-and-over in 1970, with this older age group expected to increase to more than 137 million by the year 2000, representing the largest increase of the 60-and-over population for any region of the world, that is, 154.5%.

East Asia, the region which ranked second in 1970 in total population, with nearly 927 million persons, is expected to increase to 1.3 billion by the year 2000. For both the years 1970 and 2000, East Asia ranks first in the total number of persons 60-and-over, with more than 78 million in 1970 and nearly 158 million in the year 2000. This represents an increase of more than 100% in the 60-and-over age group during this 30 year period. The 80-and-over population in East Asia, while only .6% of all ages in 1970 and 1% in 2000, will increase by 176% over this time period. This compares with an increase of nearly 48% for all ages during this same period. By year 2000, East Asia will have the greatest number of persons over age 80, nearly 15 million, and nearly 2 million more than the more developed region of Europe.

For Latin America, the increase in both the 60-and-over and 80-and-over populations is most significant, with an anticipated increase of nearly 216% of the 80-and-over population between 1970 and 2000 as contrasted with an increase of 119% for all ages.

For the more developed regions such as Northern America and Europe, the proportions of the 60-and-over population are far greater than for the less developed regions, with 13.8% of the Northern American population 60 years and over in 1970. This proportion is expected to increase to 14.5% by the year 2000. Europe, which had the highest proportion of persons 60 years and over, 16.7% in 1970, will experience an increase to 18.5% by the year 2000. For the U.S.S.R. this proportion was 12% in 1970 and will represent 17.8% by 2000. Much of this higher proportion is due to higher survival rates into middle age and the advanced stages of life in

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these economically more developed sectors of the world, as well as a decline in the number of births. Despite the higher proportions in these more developed regions, the numbers of the 60-and-over population are far less than in the developing regions of the world.

If the regions are broadly grouped into the more and less developed classifications, as seen in Table 4, in 1970 East Asia, South Asia, Africa and Latin America accounted for nearly 166 million persons 60-and-over (54% of the world's total 60-and-over population) and by the year 2000 these regions are expected to have 378.879.000 persons 60 years and over, 65% of the world's total. For the 80-and-over population, the more developed regions of Europe, Northern America, the U.S.S.R. and Oceania accounted for 57% of the world's 80-and-over population in 1970; however, by the year 2000, 53% of this age group will be found in the developing regions of East Asia, South Asia, Africa and Latin America.

It is important that sex differences be identified and their implications understood for social policy planning and service development. This is particularly important because with the aging of populations is associated an increasing survival of females over males. In the more developed countries where aging has been more pronounced in recent years, the world of advanced old age has been characterized as essentially a women's world. This is shown in Tables 5 and 6. Table 5 identifies the proportion of the 80 and over population within the 60-and-over age group for the world and its regions. The higher percentages of 80-and-over females among all females 60-and-over for the world as a whole and especially for the more developed regions in 1970 should be noted. These proportions will increase to nearly one in six older females for the more developed regions by the year 2000. The highest percentage will be found in North America which will be approaching one in five, followed closely by Europe and the U.S.S.R., each with approximately one in six women 80 years-and-over among all women 60-and-over. Men, on the other hand, have a smaller proportion in the very old age groups in every region of the world for both 1970 and the year 2000. However, their proportions in the older age group will continue to increase, particularly in the more developed regions.

Females in the more developed countries have a life expectancy at birth of 6 to 8 years greater than males, and in some developed countries this gap is widening. More women can expect to survive, on the average, to approximately 77 years with an expectation that half will survive beyond that period.

ANALYSIS OF THE PROBLEM

Until recently there has been confusion between the processes of aging and disease processes. Old age is not a cause of death. Rather, death is caused by a defined disease or pathological entity. What is known is that aging is a process of differentiation, both within the human organism and between individual human beings. A number of physiological changes appear to have a direct relationship to growing old. Despite these changes, a majority of older persons retain their functional capacities notwithstanding apparent organic decline.

In the developed sectors of the world there has been a major response to the aging of the population through an emphasis on institutionalization of the aged. It is a long-held view that older persons needed special care and protection from the stress of community life. (There is now, however, an increasing questioning of the appropriateness of this approach). It should be noted that in many countries more than 95 percent of older persons reside in the open community, and they increasingly utilize community health services and facilities. In some less developed regions there is beginning emphasis on the use of special institutions to care for the aged, based upon the models of the more developed world, but the more developed countries are beginning to provide a full range of alternative settings for "care", based upon the recognition of the individual differences and needs within the older population.

It should be borne in mind that the problem we are dealing with is extremely complex, and will require a multidisciplinary approach in the development of services. Further, it should be recognized that it is not simply a medical problem, but one which involves social, environmental and economic factors, and in analyzing such multidimensional problems the importance of the demographic trends should be constantly borne in mind, particularly the marked increase in older age groups, and the disproportionate mortality and morbidity rates between the sexes.

The indications based on an analysis of recent studies tend, however, to indicate that this group of population can be said to be generally healthy, both physically and mentally, but is often bored or lonely and many have social, vocational and economic problems of much greater importance. This statement is borne out by the results of a fairly recent survey in a large Scandinavian city, which covered 88% of all 70-year olds and produced data, not only in terms of somatic information, but also sociological, psychological and dental data, together with subjective statements of those studied regarding their life situation. Some extremely interesting and important information has been gathered and some of these findings are as follows.

At the time of the investigation slightly more than three per cent of those surveyed were in hospitals or institutions intended for both short-term and long-term stay. Two per cent needed assistance in daily activities, mainly in dressing themselves. Only one per cent needed assistance when attending the toilet, and only one in 250 needed assistance to eat. One in 200 could walk only with assistance, and one in 200 could not walk even with assistance, so in all, one in a hundred had serious problems of ambulation.

Ninety-nine per cent of those covered in the study could read newspapers and books when wearing glasses. One in four had checked his glasses during the past year. Only one per cent could not follow a normal speaking voice at a distance of one metre. Nine out of ten women and eight out of ten men could, without bending their knees, reach the floor or a point less than 10 centimetres from the floor.

The majority were mentally alert. Only two in 1000 were confused regarding their name, their birthday and the day of the week. One in 25 had signs of organic brain damage, and in addition, one in 40 was found to have a serious psychiatric disease. Some 50 per cent of those questioned would like to return to work if it were possible.

Referring to the United Nations Symposium on Research and Welfare Policies for the Elderly, held in Israel in June 1969, this comparative study showed very interesting differences between the percentages admitted to hospital during the year preceding the symposium. For example, an average of 5% in the age-group 65-69, and 70-74 were admitted to hospital for a stay of more than 14 days. The percentage, at least in this study, rose only to 6% in the age-group 75-79, but also remained at 6% in the age-group 80 and above.

This would seem to correspond with observations made in the previously-mentioned Scandinavian study, in which it was found that only one in eight among the 70-year-olds had needed a visit by a doctor during the past three years, and about half of them stated that they "never saw a doctor or a nurse" or at least had not seen one during the last year, whereas only one in four had seen a doctor or attended hospital as frequently as once every three months. This is confirmed by information from the German Democratic Republic where only one in three of the population aged 65 and over makes use of well-developed and easily accessible medical services during a given year.

These observations indicate rather limited medical problems which could possibly be confirmed, better analyzed and understood if studies on the incidence of diseases and the prevalence of impairments in the higher age-groups were available, but such studies seem to be non-existent. Mortality studies do exist, however. On the basis of studies carried out in Denmark, Israel, Norway, Poland, United Kingdom, the United States and Yugoslavia, it has been calculated that in a population of 100 000 some 900 persons in the age-group 65-and-over die annually. Of these slightly more than 500, or approximately 60 per cent may be expected to die from cancer, cerebral strokes or other cardiovascular diseases. It is certainly difficult to deduce from such statistics what the medical problems of the elderly are, but the impression is borne out that the medical problems are not as overwhelmingly great as many believe.

The social problems of the elderly, however, do seem to be very considerable. An increasing number of old people complain that they live isolated lives or feel lonely. In the age-group 65-69, roughly 20 per cent state that they sometimes or often feel lonely, and in the age-group 80-and-over this proportion rises to between 30 per cent and 40 per cent. Many factors combine to create this situation, which sometimes exists in spite of frequent contacts between the elderly and their children and friends. One underlying factor is probably the situation with regard to work. After the retirement age, which in Europe today is mainly around 65, elderly people are no longer allowed to work, even if they want to; thus they have to change their social role, and for many this seems to be a difficult task at the age of 65. Perhaps another important element is that they sometimes lose, even in their family relationships, the feeling of being needed, of being useful. These observations should be seen in the light of the available evidence that the elderly are not only in general able to work, but they are also able to learn and to adjust to change, even if many find it difficult to adjust to the loss of work.

Another aspect is linked to this, at least in many parts of Europe, which is the economic situation created by a reduced income, most often resulting from the loss of the right to work, sometimes from a gradually reduced ability to work, and sometimes from the tendency of the next generation to wish to take over full responsibility. In addition, cultural patterns exist whereby the elderly are told that they should "rest and take it easy". Only gradually, and only in some parts of Europe, is the reduced income being adequately compensated through pension schemes.

Probably these social, economic, vocational and psychological components are much more important in creating a difficult life situation for the elderly than the medical components. Nevertheless, the problem is often presented as a medical one, this apparently being more acceptable both to the individual and to society. In addition, and possibly because of this acceptability, we have created a service system which will give both economic and social advantages to those who present as medical problems. It is important to realize, however, that if a social or economic problem is presented as a medical problem it should be met and dealt with not as a medical problem but on the basis of its real causes.

PROBLEM AREAS

One of the main problems requiring investigation refers to the inadequacy of information on mortality and morbidity in age-specific groups. Nearly all the present data group the whole of this population into age 65 and over, and therefore assume wrongly that this is a homogeneous group. The differences in the need of rural and urban areas are not clearly understood, nor are the changing clinical aspects of multiple morbidity and changing attitudes in regard to family structure. If we compare the situation in the developing and developed world, it seems essential to maintain the strong family ties that exist in the developing countries and to re-establish those in the developed world which tend to have disappeared. Service development has in the past been, and possibly still is, hampered by an emphasis on "cure" rather than on "care", and by outdated and inadequate legislation. There is also lack of evaluation of present social policies. In education and training, even of professional groups, the curricula are often limited to stressing the care of individual morbidity, often in a clinical sense.

FUTURE CONSIDERATIONS

If we take as the starting point the fact that in Europe there is an increasing number of people aged 65 or older to whom we deny the right to work and who we know will in the future meet increasingly frequent social. economic, psychological and vocational problems and also medical problems and sickness, and will eventually die, most often after a fairly short period of serious incapacity or disease, then we may have a fair basis for our planning. For this group we need to develop health protection in the broad sense. We should, however, be realistic and face the fact that the prevention and treatment of diseases and impairments will have to be dealt with first. Since we do this fairly well and thus postpone death - let us always remember, incidentally, that we never prevent death - then it seems to be our duty to make sure that we also preserve the highest possible quality of life for those in this group. Perhaps we should examine to what extent this aging population may be assisted in maintaining good health, in keeping a purpose in life and in remaining alert and active. For instance, some of them could be recruited as auxiliary personnel for the health services that we so badly need but have problems in creating because of a lack of manpower.

Perhaps we should be more open to the possibility of giving the public, and especially local advisers, at least some information instead of adopting the "trade union" attitude, which also applies to health personnel, of accepting only those who are fully trained. Only gradually have the primary physician, the medical officer and the community nurse developed professional community services. Alongside this, voluntary, religious and other organizations have created some care institutions. Even more recently, organized society has gradually developed some reference possibilities for the primary physician. Gradually as the general hospital becomes more specialized through the increasing number of consultants and the specialization and sub-specialization of departments, their value to the population in general will only be seen if they act in consultation and in conjunction with the local community medical, personnel, and health services. "Health" problems exist mainly in the community, not in specialized institutions.

The problem of coordination certainly exists. In this coordination both the elderly person himself, the family and the various professionals must take part. Experience seems to show that coordination and cooperation are most effective if each participant clearly respects the limit of his own experience and legitimate interests, and thus respects the insight and integrity of the others. There is also an important consideration that resources in any country are often insufficient to meet total service demands, and realistic planning therefore must start with a consideration of priorities which can be met by existing resources.

Modern technology ensures that the provision of food, housing, clothing, home equipment and transport facilities (items that are often referred to as "production") can be sustained with much less manpower than before. At the same time, administration and various kinds of service have developed, and at present it seems doubtful whether it is possible to maintain adequate economic stability and development without some 20 per cent of the population being engaged in the production of what is regarded as necessary for the daily life of the whole population. This leaves about 10 per cent for the other main activities in a society: teaching, justice, administration and health. Teaching alone will take roughly 4 per cent. A maximum of 5 per cent of the existing manpower is therefore available for all types of "health services".

Trends do not seem to point to a greater percentage of manpower becoming available for health services. There is a tendency towards a lower retirement age and towards a longer period of education and training for young people. Both tendencies will limit rather than enlarge the roughly calculated 5 per cent. In the health services, modern technology has not, at least so far, led to any remarkable increases in output per employed person, even if minor improvements may have been achieved. Within this 5 per cent then, all health services in the broad sense of the term must be covered. This includes prevention, treatment of diseases, care and rehabilitation of persons with impairments, social services and long-term care.

CONCLUSION

The majority of research findings in developed countries stress that while dependency on other persons is a characteristic of each life-stage, there are normal dependencies related to growing old. However, many of these may be caused by society's approaches to the aging, rather than inherent in aging per se. The issue appears not to be one of dependence versus independence; rather the capacity and right to "self-care" of one's bodily, psychological and social functions. Dependency is often created by the destruction of the individual's own capacities. At times, persons working with the aging tend to take over by making decisions which are normal to other adults in the population.

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The rapid changes which are occurring throughout the world make information increasingly obsolete. Information exchanges between the elderly and the young often become complex and less relevant. The elderly often present knowledge and experiences which grow out of past identities. In addition, much of the industrial and urban areas of the world have developed a youth-oriented culture which places heavy emphasis on children and the young. Older persons are viewed as obsolete. Part of this negative attitude toward the aging may be due to an emphasis on the future; with the young symbolic of the future and the old representing that which is past.

Educational institutions have traditionally emphasized the preparation of the young for vocations. With rapid technological and social change, many occupations and professions have become obsolete without continuing education throughout their work life. Only recently have questions been raised, particularly in the more developed countries, concerning the importance of lifelong learning and the changing roles of primary, secondary, and higher education in regard to preparation for aging and for the creative use of time beyond family and occupational responsibilities. Further, there is a growing need for the preparation of persons to work in gerontologically-related fields of research, education and service.

Although there is some evidence of programmes to prepare individuals and families for retirement, these are still limited. This clearly indicates a need, if active social policies are to be developed for more epidemiological research, and that the policies should ultimately be related to functional rather than chronological age.

If it is true that the picture as indicated by epidemiological studies is that the problem is one of limited medical conditions, and if it is true that the major problems are in the social and economic fields, then much closer coordination is required between the health, social and welfare services.

Table 1. The 60 and Over and 80 and Over Populations of the World (in thousands) as Proportions of the World's Total Population for 1970 and 2000; and the Percent Change, 1970-2000.

Age	1970		2000		Percent Change
	Number	Percentage of World's Total	Number	Percentage of World's Total	1970-2000
60 and Over	304,341	8.4	581,431	9.3	+ 91.04
80 and Over	26,327	.7	57,605	.9	+118.81
All Ages	3,610,377	100.0	6,254,377	100.0	+ 73.23

Source: Population by Sex and Age for Regions and Countries, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP60, 25 February, 1976).

Table 2. The 60 and Over and 80 and Over Populations (in thousands) for the World and its More Developed and Less Developed Regions, for 1970 and 2000, as Compared to All Ages and the Percentage Distribution Between Regions; and, the 80 and Over Age Group as Percentages of the 60 and Over Population.

Age	World		More Developed Regions		Less Developed Regions	
	1970	2000	1970	2000	1970	2000
All Ages	3,610,377	6,254,377	1,084,018	1,360,245	2,526,359	4,894,133
Percentage All Ages	100.0	100.0	30.0	21.8	70.0	78.2
60 and Over	304,341	581,431	153,423	233,851	150,916	347,279
Percentage 60 and Over	100.0	100.0	50.4	40.3	49.6	59.7
80 and Over	26,327	57,605	16,097	31,203	10,230	26,402
Percentage 80 and Over	100.0	100.0	61.1	54.2	38.9	45.8
80 and Over as a Percentage of 60 and Over	8.7	9.9	10.5	13.3	6.8	7.6

Source: Population by Sex and Age for Regions and Countries, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP60, 25 February, 1976).

Table 3. The 60 and Over and 80 and Over Age Groups, Numbers (in thousands) and as Percentages of All Ages, as well as Percent Change, 1970 and 2000, by Regions of the World.

		1970		2000		Per cent Change
Region	Age	Number	Percentage of All Ages	Number	Percentage of All Ages	1970-2000
Africa	All Ages	351,727	100.0	813,681	100.0	+ 131.3
	60 and Over	15,704	4.7	42,133	5.2	+ 152.2
	80 and Over	1,235	.35	2,629	.32	+ 112.9
Latin America	All Ages	283,020	100.0	619,929	100.0	+ 119.0
	60 and Over	16,483	5.8	41,529	6.7	+ 152.0
	80 and Over	1,225	.43	3,865	.62	+ 215.5
Northern America	All Ages	226,389	100.0	296,199	100.0	+ 30.8
	60 and Over	31,276	13.8	42,965	14.5	+ 37.4
	80 and Over	3,573	1.6	7,012	2.4	+ 96.2
East Asia	All Ages	926,866	100.0	1,307,061	100.0	+ 47.8
	60 and Over	78,331	8.5	157,772	11.5	+ 101.4
	80 and Over	5,401	.58	14,916	1.1	+ 176.2
South Asia	All Ages	1,101,199	100.0	2,267,266	100.0	+ 105.9
	60 and Over	53,997	4.9	137,445	6.1	+ 154.5
	80 and Over	3,622	.33	8,479	.37	+ 134.1
Europe	All Ages	459,085	100.0	539,500	100.0	+ 17.5
	60 and Over	76,449	16.7	99,947	18.5	+ 30.7
	80 and Over	8,118	1.7	13,181	2.4	+ 62.4
Oceania	All Ages	19,323	100.0	32,715	100.0	+ 69.3
	60 and Over	2,081	10.8	3,632	11.1	+ 74.5
	80 and Over	233	1.2	438	1.3	+ 88.0
U.S.S.R.	All Ages	242,768	100.0	315,027	100.0	+ 29.8
	60 and Over	29,018	12.0	56,007	17.8	+ 93.0
	80 and Over	2,920	1.2	7,035	2.2	+ 142.6

Source: Population by Sex and Age for Regions and Countries, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP60, 25 February, 1976).

Table 4. The 60 and Over and 80 and Over Age Groups by Groupings of Selected Regions and their Proportions by such Groupings for the Years 1970 and 2000.

Region	60 and Over 1970	% of Total	60 and Over 2000	% of Total	80 and Over 1970	% of Total	80 and Over 2000	% of Total
East Asia	78,331		157,772		5,401		14,916	
South Asia	53,997		137,445		3,622		8,479	
Africa	16,704		42,133		1,235		2,624	
Latin America	16,483		41,529		1,225		2,629	
Subtotal	165,515	54.	378,879	65.	11,483	43.	29,889	53.
Europe	76,449		99,947		8,118		13,181	
Northern America	31,276		42,965		3,573		7,012	
U.S.S.R.	29,018		56,007		2,920		7,085	
Oceania	2,081		3,632		233		438	
Subtotal	138,824	46.	202,551	35.	14,844	57.	27,716	47.
TOTAL	304,339	100.	581,430	100.	26,327	100.	57,605	100.

Source: Population by Sex and Age for Regions and Countires, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP60, 25 February, 1976).

Table 5. The 80 and Over Age Group as a Percentage of the 60 and Over Age Group, by Sex for 1970 and 2000, for the World and its Regions

Area	1970 Male %	1970 Female %	1970 Both Sexes %	2000 Male %	2000 Female %	2000 Both Sexes %
World	7.07	9.90	8.65	8.05	11.46	9.90
More Developed	8.11	12.12	10.49	10.13	15.71	13.34
Less Developed	6.18	7.32	6.77	6.82	8.31	7.59
Africa	7.13	7.60	7.39	5.70	6.69	6.23
Latin America	6.57	8.19	7.43	8.12	10.32	9.30
Northern America	7.23	14.65	11.42	13.38	18.42	16.32
East Asia	5.97	7.71	6.89	8.04	10.73	9.45
South Asia	6.24	7.17	6.70	5.78	6.52	6.16
Europe	8.65	12.03	10.61	10.11	15.58	13.18
Oceania	8.87	13.08	11.19	9.97	13.88	12.05
U.S.S.R.	8.41	10.84	10.06	8.31	15.48	12.65

Source: Population by Sex and Age for Regions and Countries, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP60, 25 February, 1976).

Table 6. The 60 and Over and 80 and Over Populations of the World, the More and Less Developed Regions, and by Major Regions (in thousands) by Sex; as Percentages of Males and Females in All Ages; and the Ratio of Males to Females, 1970 and 2000.

Area	1970					2000				
	Male		Female		Sex Ratio	Male		Female		Sex Ratio
	Number	% Male	Number	% Female		Number	% Male	Number	% Female	
					Age 60 and Over					
World	135,228	44.43	169,113	55.57	79	265,506	45.66	315,925	54.34	84
More Developed	62,543	40.77	90,880	59.23	68	99,490	42.54	134,361	57.46	74
Less Developed	72,685	48.16	78,231	51.84	92	165,715	47.72	181,564	52.28	91
Africa	7,708	46.14	8,996	53.86	85	19,358	45.94	227,777	54.06	84
Latin America	7,746	46.99	8,738	53.01	88	19,242	46.33	22,286	53.67	86
Northern America	13,628	43.57	17,646	56.43	77	17,905	41.67	25,059	58.33	71
East Asia	36,714	46.87	41,619	53.13	88	75,150	47.63	82,620	52.37	90
South Asia	27,144	50.27	26,854	49.73	101	66,168	48.14	71,275	51.86	92
Europe	31,980	41.83	44,470	58.17	71	43,828	43.85	56,120	56.15	78
Oceania	935	44.93	1,146	55.07	81	1,694	46.65	1,937	53.35	87
U.S.S.R.	9,373	32.30	19,645	67.70	47	22,158	39.56	33,849	60.44	65
					Age 80 and Over					
World	9,571	36.35	16,756	63.65	57	21,387	31.13	36,218	62.87	59
More Developed	5,076	31.53	11,021	68.47	46	10,082	32.31	21,121	67.69	47
Less Developed	4,495	43.94	5,734	56.06	78	11,305	42.82	15,097	57.18	74
Africa	550	44.57	684	55.43	80	1,104	41.98	1,526	58.02	72
Latin America	509	41.55	716	58.45	71	1,564	40.47	2,301	59.53	67
Northern America	986	27.60	2,586	72.40	38	2,396	34.17	4,616	65.83	51
East Asia	2,192	40.58	3,210	59.42	68	6,046	40.54	8,869	59.46	68
South Asia	1,695	46.80	1,927	53.20	87	3,829	45.16	4,650	54.84	82
Europe	2,767	34.08	5,352	65.92	51	4,435	33.65	8,746	66.35	50
Oceania	83	35.62	150	64.38	55	169	38.58	269	61.42	62
U.S.S.R.	789	27.02	2,131	72.98	37	1,843	26.01	5,242	73.99	35

Source: Population by Sex and Age for Regions and Countries, 1950-2000, as Assessed in 1973: Medium Variant (U.N., ESA/P/WP66, 25 February, 1976).

INTERNATIONAL YEAR FOR DISABLED PERSONS

Esko Kosunen*

ABSTRACT

The United Nations has proclaimed 1981 the International Year for Disabled Persons with the theme "full participation". The Year will be devoted to the realization of certain objectives aimed at promoting the rehabilitation of disabled persons and their integration into society. A long-term programme of action aiming at the realization of those objectives and the implementation of the Declaration on the Rights of Disabled Persons will be prepared.

Different kinds of activities in observance of IYDP are expected to be organized in all countries. Three different United Nations expert groups have recently studied different kinds of obstacles to the full integration of disabled persons into society and to the provision of rehabilitation services. Their recommendations aim at eliminating physical and social barriers and clarifying the socio-economic implications of rehabilitation investments. IYDP may be used to help implement their recommendations. The IYDP secretariat functions at Geneva preparing international observance of IYDP. Ideas and support for programmes particularly in developing countries are most welcome.

OBJECTIVES OF IYDP

The International Year for Disabled Persons was proclaimed by the United Nations General Assembly at its thirty-first session in 1976. In proclaiming the Year the Assembly reaffirmed "its deep-rooted faith in human rights and fundamental freedoms, the principles of peace, the dignity and worth of the human person and the promotion of social justice" as proclaimed by the Charter of the United Nations and also recalled its previous resolutions on the Declarations on the Rights of Mentally Retarded Persons and on the Rights of Disabled Persons. The Assembly gave the Year the theme "full participation" and decided to devote it to the realization of a set of objectives including:

"a) helping disabled persons in their physical and psychological adjustment to society;

b) promoting all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available opportunities for suitable work and to ensure their full integration in society;

c) encouraging study and research projects designed to facilitate the practical participation of disabled persons in daily life, for example, by improving their access to public buildings and transportation systems;

d) educating and informing the public of the rights of disabled persons to participate in and contribute to various aspects of economic, social and political life;

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e) promoting effective measures for the prevention of disability and for the rehabilitation of disabled persons."[1].

These objectives do not directly refer to the theme of this conference, "Disability in the Family", but, I believe, they can be considered also in the context of that theme as well as taken in a more general sense. As reference is made to the Declaration on the Rights of Disabled Persons, the Assembly obviously wanted to make it clear that the proclaimed rights and their implementation should be considered when activities are planned for the observance of the International Year. In fact, the Assembly already has approved the preparation of a long-term programme of action which should be one of the principal outcomes of the Year and the purpose of which is to promote the implementation of the principles of the mentioned Declarations as well as the objectives of IYDP. The adoption of this programme of action by the General Assembly at its thirty-sixth session in 1981 is expected to be the final act of the Year.

It is in this context that the objectives of IYDP can be brought closer to the theme of this conference. The Declaration lists as one of the basic rights of disabled persons the right to live with their families or with foster parents and to enjoy a decent life, as normal and full as possible. The tone of the entire Declaration is set towards favouring the fullest integration of disabled persons in society. Accordingly, it favours the promotion of rehabilitative measures that will help disabled persons to remain with their families or to establish their own families and to be able to participate in all aspects of the life of the community they live in.

In preparing activities for IYDP, the United Nations Secretariat will give a high priority to the establishment and development of rehabilitation services, particularly in developing countries, through which full participation can be achieved. It is hoped that Governments and the interested organizations, particularly in Europe, will decide to observe the IYDP, to support the efforts of the United Nations for the benefit of developing countries and to undertake themselves specific measures and activities aimed at the achievement of the Year's objectives and the implementation of the rights of disabled persons in their respective countries. I am convinced that this conference will greatly enhance the preparation of the IYDP programme as it can point out some of the most important problems, and may suggest means of solving those problems, that should be taken into account in finalizing the Year's programme of activities. It is my privilege on this occasion to report to you on the work that has been done in this regard within the United Nations' social development programme in recent years as well as on the on-going preparatory work for IYDP.

Even before the proclamation of IYDP, efforts had been undertaken by the United Nations Secretariat to consider certain particular questions that, perhaps, represent the principal obstacles to the fullest possible participation of disabled persons in community life. Three expert groups have been convened in recent years to deal with the following three subjects respectively: architectural barriers, discriminatory and prejudicial attitudes, and investments in rehabilitation. These expert groups were convened in 1974, 1976 and 1977 respectively and the recommendations of these groups, it is hoped, will help remove the obstacles that prevent full participation by disabled persons. The first-mentioned subject was also dealt with, to some extent, by HABITAT:

United Nations Conference on Human Settlements, which adopted a number of recommendations that included references to the specific requirements of disabled persons for an accessible environment and to their participation in efforts to create that kind of environment.

In the following I shall summarize briefly the conclusions and recommendations of each of the mentioned expert groups without going into the details of the deliberations and reasonings that preceded the adoption of those recommendations. I shall make an effort to limit myself to those of them that are related to the subject-matter of this conference.

BARRIER-FREE DESIGN

The expert group that considered this subject tried to find ways of making society barrier-free for all, including the severely disabled and, in particular, to study measures of rendering dwellings accessible to and habitable and usable by them. It concluded that the elimination of environmental barriers would help prevent unnecessary segregation of disabled people and their relegation by society to less mobile living. It adopted certain functional requirements that must be met in order to provide for accessibility and expressed the view that "buildings, habitable spaces and transportation systems usually can be designed to accommodate disabled people without complicated or expensive devices or modification of standard design". The group recommended, among other things, that

"a) The United Nations and other interested organizations consider ways for

(i) promoting international guidelines affecting policies on barrier-free design;

(ii) stimulating and co-ordinating the work that is being done in this field;

(iii) allocating funds for a clearing house of information specializing in barrier-free design of buildings and facilities;

(iv) promoting research on architectural and other physical barriers and on their elimination;

(v) following up the implementation of the recommendations of the meeting;

(vi) assisting developing countries which wish to know why and how to make their buildings and facilities free of impediments to handicapped people.

b) The 1976 United Nations Conference Exposition on Human Settlements include examples of barrier-free design and consider the ideas and recommendations expressed by this meeting in selecting the model communities to be included in its programme."[2].

The HABITAT conference did not directly consider the recommendations of the expert group but the assembly of official delegates picked up ideas and views raised at the simultaneous informal forum meetings in which special attention had been given to the problems that disabled persons encounter in modern society. The views expressed at these meetings found their way into some of the recommendations of the official sessions suggesting, among other things, that the special interests of children, the elderly and the handicapped should be taken into account in neighbourhood planning, in designs and technologies for shelter, infrastructure and services and transportation and communication, and that procedures should be adopted to facilitate the active participation of the handicapped and other vulnerable groups of society in the planning of human settlements and in decision-making processes concerning those settlements [3]. In response to a subsequent resolution of the United Nations General Assembly [4], a report on the implementation of these particular HABITAT recommendations concerning disabled persons, the elderly and children has been before the Economic and Social Council at its session in July 1978 (as this paper was written in June the outcome of the ECOSOC discussion on this subject was not yet known). As one of the possible activities for IYDP, the preparation of a manual is being considered that would, among other things, deal with such architectural and other man-made factors which people can modify themselves and thus make the environment habitable and usable by disabled persons even in countries and regions where more sophisticated means for eliminating such barriers are not available.

SOCIAL BARRIERS

The expert group on social barriers to the integration of disabled persons into community life considered, among other things, the prejudices and discriminatory behaviour that may impede the integration process. In this context, it gave special attention to the way prejudices and discriminatory behaviour affect family life. The group concluded that "family life may create or minimize social barriers to the integration of disabled people, depending upon the nature of the family interaction as well as the number of societal factors affecting family life". The ambivalent attitudes of other family members towards the disabled member of the family, often perhaps reflecting a mixture of ignorance, fear and over-concern, may lead to over-protective attitudes and thus create barriers to social integration. On the other hand, the family's understanding of the problems of the disabled family member and its support to the latter's efforts to find a place in society may often help minimize social barriers and, in fact, become a decisive factor in a successful integration process.

The group emphasized that in order to avoid unnecessary segregation disabled persons should have an opportunity to live independently. It recognized that family and societal attitudes often reinforce concepts of the traditional rôle of girls and women in society in general and recommended therefore that special attention should be given in the planning and carrying out of rehabilitation programmes to ensure a proportional participation of disabled girls and women in all aspects of community life. The group further recognized the importance to disabled persons of an harmonious family life and the ability to establish intimate relationships, marry and function adequately in those relationships, and recommended that sexual rehabilitation should be an integral part of the normally available rehabilitation programmes whenever a disability interferes with sexual functioning.

In general, the expert group noted that there were many misconceptions and much ignorance on the part of the general public about different kinds of physical and mental disabilities and their effects on the persons who suffer from them, as well as about the possibilities that rehabilitation services offered for diminishing and overcoming many of the adverse effects of disabilities. The group recommended therefore that models of direct and indirect community education about disabilities, disabled persons and their rehabilitation should be devised. In this context, special attention should be paid to eliminating the perpetuation of stereotypes of and prejudicial attitudes towards the disabled in young children in particular. It was the view of the group that disabled persons should be given an opportunity to involve themselves directly in the initiation, planning and outcome of their own rehabilitation programmes and be encouraged, individually and in groups, to initiate programmes that would facilitate and enhance their own social and economic integration. Family life, naturally, should be a part of the integration process.

INVESTMENTS IN REHABILITATION

The third recent United Nations expert group in rehabilitation matters dealt with the question of the social and economic implications of investments in rehabilitation. These implications do not affect only disabled persons but, to a great extent, also the family and community as well.

The group noted that often when the costs of rehabilitation services are counted and then presented as an overwhelming obstacle to the provision of the services concerned, there is a tendency to count even those services that while being a part of a rehabilitation process are also available, under certain conditions, to the population as a whole under general health, education, social security and social welfare programmes. It was the group's view that only the differences between specific rehabilitation services provision and the services available under general social programmes should be counted as rehabilitation expenditure. The group furthermore noted that in measuring the implications of investments in rehabilitation services, the benefits that other members of the family may obtain as a result of a successful rehabilitation of the disabled family member may not always be given full credit. One readily admits that many of these benefits may be immeasurable or at least extremely difficult to measure exactly, such as relief from anxiety, lessening of tensions within the family, more freedom for family members and other similar benefits. Some of the benefits, on the other hand, can well be measured and should be taken fully into account in analysing the usefulness of investments in rehabilitation, i.e. reduction in the time required to attend on a severely disabled family member.

In general, the group noted that when the adverse effects of a disability as well as the benefits of rehabilitation are assessed, those factors that affect the whole family should also be taken into account. The group emphasized in particular that neither the costs of disability nor the benefits of rehabilitation should be assessed only in monetary terms. Various psychological factors that affect the life of disabled persons, their spouses, parents and children at home should also be taken into account. The group emphasized furthermore the need for a

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form of negative measurement, that is measuring the effects of providing no rehabilitation services and its impact on the family. The group recognized the many difficulties that exist in arranging such measurement on an experimental basis as it would require control groups to whom rehabilitation services would have to be denied for a certain period of time. It is much regretted that the report of this expert group is not yet available as it would have provided, I believe, much useful material for your conference.

In reference to all three expert group meetings, it is regretted that their recommendations have, perhaps, remained largely unnoticed and that very little has so far been done to implement them on either the international or national levels. I hope, however, that the International Year for Disabled Persons will provide an opportunity to draw the attention of the Government authorities concerned as well as of other interested groups to these problems and the possibilities of solving them. Any programme aimed at the implementation of the objectives of IYDP or the Declaration on the Rights of Disabled Persons should take these recommendations into account.

PREPARATORY WORK FOR IYDP

At its thirty-second session in December 1977, the General Assembly authorized the Secretary-General to undertake certain measures in the preparation of IYDP activities [5]. Accordingly, a small IYDP secretariat has been set up in the United Nations Office at Geneva and an Advisory Committee for IYDP, comprising the representatives of 15 countries and representing all major geographical regions of the world, has been appointed and had its first session in August (when writing this paper the outcome of this meeting was not yet known). The Committee will submit its proposals concerning the programme and budget of IYDP to the United Nations General Assembly at its thirty-fourth session in 1979. Before formulating its final proposals, the Committee is expected, and has been requested by the General Assembly, to consult Member States and organizations concerned on the IYDP programme. It is therefore possible for the Governments of your countries as well as the Rehabilitation International to take part in the process and the discussion of the Committee's proposals in the General Assembly late next year. In this connexion I should like to mention that the United Nations Commission for Social Development will have before it, at its next session in January-February 1979, a report on the implementation of the Declaration on the Rights of Disabled Persons. Several European countries are members of the Commission, including the host of this Conference, and will thus be in a position to express their views on the present status of implementation of the Declaration and on the measures required for a better and fuller compliance with its provisions.

One of the IYDP activities the General Assembly already has approved is the preparation of a long-term programme of action for the implementation of the objectives of the Year and the principles of the Declaration on the Rights of Disabled Persons, as I have already mentioned. A broad outline for this programme has been prepared and the further elaboration of the document will proceed along the lines approved by the Advisory Committee for IYDP at its recent session and, hopefully, in close cooperation with the RI Charter for the Eighties group. When preparing the document we will be pleased to receive ideas and proposals from all interested groups and individuals and we hope, in particular, that groups representing disabled persons themselves will contribute to its preparation. The results of this Conference will, of course, be taken into account.

A number of other proposals for IYDP activities are under consideration. Consideration is being given, for instance, to the adoption of an international convention on rendering the means of international passenger transportation accessible to all, including users of wheelchairs. In addition, a high priority will be given to the possibility of assisting developing countries in planning activities for IYDP and in the development of long-term programmes for the achievement of IYDP objectives. In this connexion, I should like to mention that a trust fund for IYDP has been established in Headquarters in New York for the purpose of receiving voluntary contributions from Governments, organizations and others interested in promoting IYDP activities in developing countries in particular.

A public information programme on IYDP is being prepared by the United Nations Office of Public Information and hopefully will be launched early next year, if not before. It is expected, among other things, that brochures and posters on IYDP will become available and that an IYDP newsletter will start appearing.

As far as Europe is concerned, it is planned to organize in 1981 within the European Social Development Programme a European seminar on a subject related to IYDP. For your information I should like to mention that the European Social Development Programme is a joint effort of the ministries of social welfare of European countries and that the participants in the seminars organized under that programme are usually appointed by those ministries. We hope that many other events will also be organized at the European level by the interested Governments and organizations and that different kinds of activities will be carried out in every European country. The United Nations has recently suggested to all Governments the appointment of an agency or official to liaison with the IYDP secretariat at Geneva in order to facilitate the exchange of information. It has also been suggested that national committees be established to plan a co-ordinated national programme for IYDP in each country. By the end of June, several countries had already announced the appointment of a liaison agency/officer and national committees or equivalent inter-ministerial working groups for IYDP had also been established in some countries.

The International Year for Disabled Persons can be made a successful event only with the full co-operation of Governments and the interested voluntary organizations. We expect in particular that Rehabilitation International and all its national affiliates will take an active rôle in the observance of IYDP. One cannot expect that the objectives of IYDP could be fully achieved during that year but it is hoped that the efforts that will be undertaken will, in the long run, lead to significant improvements in the services for rehabilitating disabled persons and will improve the possibility of disabled persons to participate fully in all aspects of community life. I should like to urge you all to take an active interest in the IYDP, to promote its observation in your respective countries, and, as one of the first steps, to bring together all the interested groups in your countries for the preparation of a concerted national IYDP programme of activities.

REFERENCES

1. General Assembly resolution 31/123 International Year for Disabled Persons.

2. Rehabilitation International, Barrier-free Design - Report of a United Nations expert group meeting, p.31, New York 1975.

3. United Nations, Report of Habitat: United Nations Conference on Human Settlements, New York 1976 (Sales No. 3.76.IV.7).

4. General Assembly resolution 31/113 Specific measures to meet the need for a decent living environment for the most vulnerable groups of society.

5. General Assembly resolution 32/133 International Year for Disabled Persons.

Seminar 4

TECHNOLOGY

Chairman: *Mr. P. J. Lowe*

The Application of Modern Technology to Rehabilitation
A. J. Solman

Systems for the Deaf
ir. A. S. Kruijf

TECHNOLOGY

Chairman: *Mr. A. R. C. Rowe*

Myoelectric Controlled Hand Protheses in Children—Clinical Considerations
Dr. Rolf Sörbye

Utility of a Communication Aid to Comprehensive and Co-operation in Family Life and the Trials and Tribulations of its Manufacture
Oliver Butler/J. F. Fouldes

NATIONAL PRESENTATIONS

Chairman: *Mrs. C. R. C. Harris*

Integrating the Disabled within the Community: The Hong Kong Approach
Mr. Ian Strachan

Disability in an Indian Family
Raghunandan Prasad

FREE PAPERS

Chairman: *Mrs. Greta Nordlie*

Social Diagnosis and Therapy in the Reinsertion of Handicapped People into Family Life
Prof. Dr. Octavian Berlogea

Integrating of the Physically Handicapped Child in the Family and Community in a Developing Country
M. Graca Andrada/Antonia Goulas

TELEPHONE FOR THE DEAF

A.S.T. Kruijf, R. Hak[+]

ABSTRACT

In order to make it possible to communicate between the deaf or between deaf and hearing people via normal telephone lines, we designed a writing tablet and a display system.
Running handwriting that is written on the tablet at one side of the telephone line is displayed on the screen of the display at the other end of the line. The system can be used by everybody who can write, because it has no keyboard. The receiving display tube has a short storage. Not all the writing is visible, only part of the last written word. According to deaf people, this is an advantage, because they do not like to write when their writing is stored indefinitely, in the same way that normal speaking people don't like to speak when their voice is recorded on a tape recorder on the other end of the line.

This two-year project is now in the beginning of the second year. Two prototypes have been realized and can be demonstrated. We will proceed by making at least ten "telephones for the deaf" which will be distributed among deaf people, in order to test the system in daily practice.

The results of this test will be evaluated. A report with all the data necessary to reproduce the system will be offered to any industry that is interested in producing the apparatus on a larger scale.

INTRODUCTION

For some years there has been a research project in progress at the Department of Electrical Engineering at the Delft University of Technology (the Netherlands) in the field of graphic telecommunications.

Running handwriting can be transmitted via a radio or telephone channel, and on the receiving side, can be displayed on an XY display or video scan display which is well known as the domestic television receiver.

The main advantage of this system, compared with the usual video systems, is that transmission of this signal can be done within a fraction of the limits of a voice channel, in contrast to a TV signal which requires a channel capacity of about 1000 voice channels.
This is due to the fact that only changes of the written picture are transmitted, hence only the location of the points that the penpoint touches are transmitted to the receiver. At the receiving side, use is made of a memory that contains all the data of the picture.
This memory is read out about 50 times per second on the display tube in order to obtain the impression of a stable picture of all the written text.

Applications of this technique are:

1. Education in third world countries. TV pictures of handwriting and drawings can be transmitted via a normal short wave audio trans-

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[+] Staff members of the Department of Electrical Engineering, Delft University of Technology.

mitter over a long distance. This feature is especially valuable in countries when there is a lack of qualified teachers and when a large archipelago consisting of small islands has to be covered.

2. One of the northern provinces of the Netherlands, named Friesland, is bilingual. Due to another ethnic origin of the Frisians their language is regarded as an important cultural heritage. Lessons in reading and writing of the Frisian language at primary schools are supported by the Dutch government. New literature is still produced. Unfortunately few teachers are masters of writing the Frisian language. This graphic system for transmission of video pictures opens up the possibility of accompanying the lessons by written information.
   In fact the normal TV transmitter is used in order to avoid the required converter at the receiving side. Advantages here are now obtained in the field of producing and editing the program. The costs are only a small fraction of the costs required for producing a regular TV program with the same purpose.

3. Writing by telephone (scribophone) applications are or can be in the field of:
   a) feeding back questions by telephone to a television open university teacher
   b) verifying signatures, including speed parameters by banks
   c) other commercial use, such as aid in conference circuits.

Thinking on graphic communication via telephone lines from person to person, there are two possibilities: typing and writing. Comparing typing with writing, we have some obvious differences:

typing:
- The number and size of possible letter pictures are strongly restricted; in general personal characteristics of writing are lost.
- It is not possible to draw.
- Typing skill is required.

writing:
- Writing and drawing is possible, with letter size and shape as produced by the writer.
- Asking the attention of the reader by pointing with the pencil to a point is also possible.
- It is possible to correct and erase all or a part of the picture.
- No special typing skill is required. The skill of writing is very widespread, in contrast to typing.

The realised scribophone has the choice of display on an XY tube or a television tube or as a hard copy on a modified printing unit. Simultaneous writing and speaking via a regular public telephone line is realised.

Of course there is an obvious application for deaf people. Due to these devices deaf people can communicate via normal telephone lines with other deaf or hearing people.

However, during the time that this writing telephone is not really as widely spread as our normal telephone and television sets, the purchase price will be prohibitive for private people.
Yet there are possibilities for lowering the price of such a system to an acceptable level.

TELEPHONE FOR THE DEAF

Costly parts of the scribophone are:

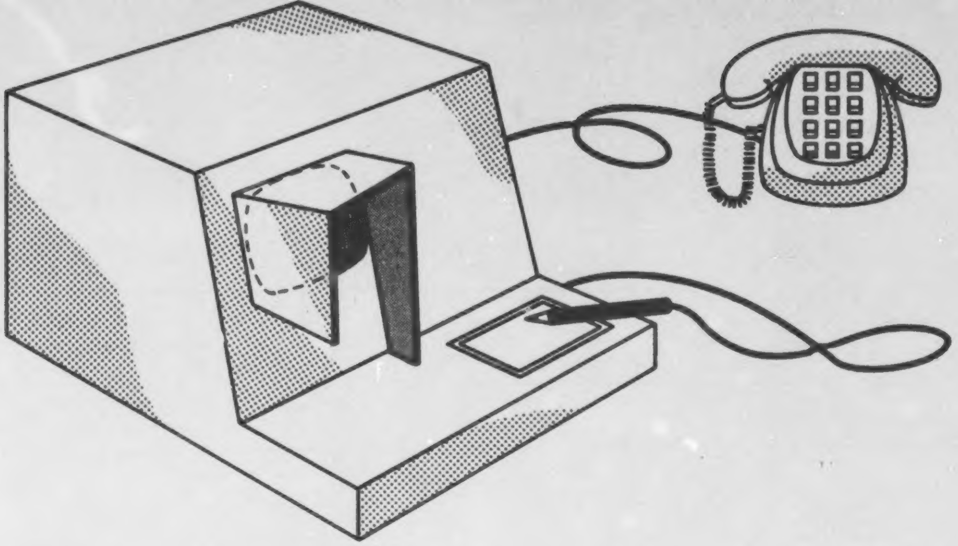
- The parts of the system that make it possible to speak and write simultaneously.
- The memory that contains the received writing in coded form and that is read out repeatedly in order to get a picture of all the received writing.

First of all we know that deaf people don't require the option of speaking and writing simultaneously.
Furthermore we can try to omit the memory. The handwriting is then received as just a moving pen point on the screen. Without special training it will be impossible to read this writing without "ink trace".

An inexpensive compromise is possible, when we make use of a display tube with a long persistence phosphor. The memory function is then present in the form of the decay time of the phosphor that was activated by the pen-point spot.
A disadvantage is that the reader is required to watch the screen during the writing, because the light trace of the pen point decays fast.
With this system that we called "telephone for the deaf", it is possible to read received handwriting without training.
Deaf people told us that they experience it as an advantage that the picture of their writing decays, in analogy to the spoken word; just as hearing people who know that their voice is recorded on a tape recorder at the other end of the line do not speak so freely, deaf people feel the same when they know that on the receiving side of the line a copy of their writing is made.

REALISATION OF THE SYSTEM

Large electronic industry has extensive capabilities for basic and applied research and development. However, by their nature they are mainly interested in mass production.
Small electronic industry is mainly interested in production of small series of equipment. However,they are not able to invest in research and development for small scale projects with a high level of technology.
One of the tasks of the universities is to assist small industry by generating novel ideas and demonstrating their feasibility.
This is done, but still this is not enough to enable small industry to produce equipment without costly development of final reproducible models for reproduction.
In cooperation with the Netherlands Society for Rehabilitation who supplied funds for two man years of labor plus the parts, we could go a step further.
We set up a two year pilot project. Between ten and twenty reproducible models have to be produced after doing all the development for making reproducible devices. At the end of this project, now in the first part of the second year, a test will be conducted in order to find out how deaf people appreciate the device. In the second quarter of 1979 the results of this test and all the technical data, schematics and printed circuit lay outs of the proven design, will be available to interested small industry.



A telephone for the deaf

FUTURE PLANS

We are looking for a method to realise variable persistence in an electronic way. When this goal is reached the evolutionary paths of the telephone for the deaf and the scribophone will meet again.
One requirement is that the persistence of the display, which is the time that a picture is readably displayed, is choosen by the writer. The receiving side will not have the option of saving the received picture when the writer does not explicitly desire that.

DEMONSTRATION OF AVAILABLE PROTOTYPES

Mr Hak will give a demonstration. Deaf people preferably are invited to use the two devices during the breaks.

HOW TO USE THE TELEPHONE FOR THE DEAF

1. The device is inserted between the wall outlet and the telephone that was plugged into that outlet. This can easily be done because the device has its own male and female telephone plugs. The device can be carried to any other subscriber phone supplied with outlet and plug.

2. When the device is switched on, normal use of the telephone by hearing people is possible without impairments.

3. A deaf person can make a connection with another subscriber due to the built-in tone detector for the first and second dial tones, or eventually a busy signal, which indicates that he has to start over again. Hence he has a visible way of checking the proceedings making up his connection.

4. The ringing signal at the receiving side is detected in the usual way for hearing-impaired people, by a flashing light or other means.

5. The called subscriber can then pick up the receiver, and start writing or receive writing.

6. Both parties can write but not at the same time. An automatic switching system detects who is writing and gives him the line. When the writer stops writing or makes a pause, the other person can start writing.

7. The communication can be finalised by placing the receiver back on the telephone on both sides. When both parties don't write the line is available for normal speech communications.

MYOELECTRIC CONTROLLED HAND PROSTHESES IN CHILDREN.

CLINICAL CONSIDERATIONS.

Rolf Sörbye

ABSTRACT

In May 1971 the first pre-school child was supplied with a myoelectric controlled hand prosthesis at the Regional Hospital in Örebro, Sweden. Up to now some 30 pre-school children have been fitted with such prostheses at this hospital, the youngest ones being 16 months of age. The acceptance of such prostheses is clearly better than in adults, but for achieving good results there are many things to be considered: The parents must be thoroughly and adequately informed, the training must be properly followed up in close co-operation with the parents, psychological factors must be regarded, and possibilities of rapid adjustments and repairs are needed. By thoroughly undertaken appliance and follow up an early fitting may lead to great benefit in suitable cases.

INTRODUCTION

Earlier it was generally thought to be more or less impossible and perhaps even contraindicated trying to supply children within and below the first school years with myoelectric controlled hand prostheses. Of that reason no such prosthesis suitable for these ages was to be found when we at the Regional Hospital in Örebro, Sweden, decided to supply a 3 year old girl with such one. Therefore, in May 1971 we supplied her with the smallest available myoelectric controlled hand prosthesis, which now, more than 7 years later and at 10 years of age is of suitable size for her [1]. Despite the big size and heavyness of the hand the first trials in this girl and a few other children were successful. However, we did feel the need of a smaller myoelectric controlled hand prosthesis, and such one was developed in co-operation with the company Systemteknik AB in Stockholm, the cosmetic cover and the glove being produced by the company Centri Gummifabrik AB [2]. From January 1976 this small myoelectric controlled hand prosthesis has been clinically tested at the Regional Hospital in Örebro, being fitted to some 25 pre-school children. The youngest ones were 16 months at the application.

Especially the last half year there has been a rapidly growing interest concerning the supplying of pre-school children with myoelectric controlled hand prostheses. Of that reason our experience from the last 7 years and from more than 30 patients fitted with such prostheses in the pre-school age might perhaps be of some practical value.

THE SMALL MYOELECTRIC CONTROLLED HAND PROSTHESIS

Based on our experiences from the Otto Bock myoelectric hand prosthesis (size 6 3/4") and a smaller Canadian prosthetic hand (from Variety Village)

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built into myoelectric control in Örebro, the co-operation with the companies Systemteknik AB and Centri Gummifabrik AB resulted in the small size muscle controlled prosthetic hand suitable for the ages 2 - 6 years. The closing time from full opening is 1 second and the pinch force is about 1,2 kg. Opening width is 50 mm, and the length without rotation module 100 mm. The weight with inner cosmetics and wrist rotation module is 210 g. The system voltage is 6V, and the maximum current consumption 350 mA. The hand has a three-point grip and a mechanical design allowing easy exchangeability of the different details, such as motor, gear box, locking mechanism, fingers and electronics. Transistors have been chosen for the control system, which is of on/off type. The electronics have been placed inside the hand itself, enclosed in araldite. Of cosmetic reasons and as a shelter the fingers and the hand details are surrounded by a plastic cover. The passively adjustable rotation module permits almost 360° rotation.

The prosthetic hand is mounted on a plastic socket, being thoroughly made for the individual patient and properly adjusted. In very long stumps it may be necessary to abandon the rotation module.

The glove, made by Centri Gummifabrik AB, does finish the cosmetic appearance.

SPLIT HOOK OR MYOELECTRIC HAND PROSTHESIS ?

Concerning prosthetic fittings in children, the question arises if it is indicated to choose myoelectric controlled hand prostheses instead of wire controlled split hooks. Both types have their advantages and disadvantages. The split hook is lighter and not very vulnerable, in many situations it has a better grip function, and it does not need any external power. The myoelectric controlled prosthetic hand, on the other side, has a better appearance and no shoulder straps, is quite independent of the positions and the activities of other parts of the body, it is controlled in a more physiological way and gives adequate training of the actual extremity muscles. It is also more acceptable from psychological point of view and may sooner and easier cause a body image in the prosthesis.

Many clinical and other factors have to be taken into account before the decision is made concerning the type of prosthesis to be chosen. If both types of prosthetic devices are available, the parents' opinion should very strongly influence that decision, after being thoroughly informed by the experts concerning the qualities of both types and their possibility of being applied in the individual case.

SUITABLE FITTING AGE

When supplied to adults, it is a common experience that the myoelectric controlled hand prostheses have often been rejected, especially by congenital amputees and after "older" surgical amputations. Many patients have found them to be somewhat slow in operation and even limited in function in many professions, and also difficult to control with the residual stump muscles. Even the more widely used wire controlled split hook has often been rejected after fittings in adults, who perhaps for many years have been used to managing with the remaining stump [3]. During the last 10 - 15 years it has become clear that the acceptance of the split hook is better the earlier it is applied, down to below the age of 2 years [4].

Still there are experts maintaining the point of view, that an application of a myoelectric controlled hand prosthesis should not be undertaken until about 16 years of age or eventually a few years earlier. The reasons are thought to be the complexity of this type of device, the difficulty for the patients to select the activities from the two antagonistic muscle groups in the forearm stump, and the difficulty of communicating with a child in an effective way during the training periods.

In our opinion it is a great advantage starting even with the myoelectric controlled hand prosthesis at a very early age [5]. There is no need of explaining to small children how the prosthesis is working. Children teach themselves how to walk, and in the same way they discover how to control the prosthetic hand. As a matter of fact, if the socket has been properly made and the electrodes correctly mounted, almost all our patients being more than about 2 1/2 years of age have been able to consciously open and close the prosthetic hand within some few minutes after the fitting. Only a few weeks later a built-in event counter has indicated 2000 - 3000 openings a day in some of them. A second prosthesis is soon needed as a reserve.

Five patients being supplied with the small myoelectric hand prosthesis at 16 - 18 months of age have demonstrated spontaneous movements of the prosthesis during playing already from the beginning. As an exception we were able to observe already the first day in one of them, a boy aged 17 months, some openings of the hand which seemed to be consciously done. He several times did open the prosthesis when his mother opened her own hand and told him to do the same.

As far as our present experience goes the most suitable age for an application of a myoelectric hand prosthesis in congenital amputees is between 2 1/2 and 4 years. Most patients in these ages have been accepting the prosthesis as a part of their body, feeling more natural with the prosthesis than without. On the contrary the few patients being fitted at a higher age, 5 - 6 years old, usually feel most natural without the prosthesis. The latter have been more used to a one hand pattern, while the former have achieved a greater ability of using the prosthesis more automatically, having also demonstrated a greater ability of using the grip function in a proper way with neither visual nor auditive feedback. By very early application the ability of using the feedback information from the vibrations of the hand motor is supposed to be even greater. We are investigating this field now.

The aim of fitting the children at the age of 16 - 18 months mainly is to get the children used to the weight of the myoelectric prosthesis and also to give them the possibility of detecting how to use this prosthesis more consciously when the proper time comes. These applications have quite recently been made, and not until 1 - 2 years from now we will be able to tell if this very early fitting age will be even more advantageous.

To make the children get used to the socket itself we recommend starting with some form of passive prosthesis at an even earlier age, before 1 year, and even better before 6 months of age. Even at that early age we have observed an obvious cosmetic factor. A couple of the small patients have clearly preferred a passive prosthesis with fingers compared to such one with only a mitten.

In order to make easier the change from the passive prosthesis into the myoelectric hand we have recently started practising a method of making the former successively heavier by putting into the wrist region of the prosthesis more and more lead hails, which has proved to be successful.

INFLUENCE OF PREVIOUS HOOK EXPERIENCE

From our experience it seems to be an age period in which there may be difficulties in changing into the myoelectric type of prosthesis from previously using a split hook. Even in children 5 years of age, being clever with their split hooks, we have noticed that they have been less motivated for the necessary training with the new device. This again has led to a less efficient function of the new prosthesis. Even of that reason it is very important that a sufficiently educated medical staff can guarantee the individual patient the possibility of a proper training and follow up on the local level, in close co-operation with the parents.

We have, however, seen children in the ages 12 - 14 years, very clever with their split hooks, who have efficiently changed into muscle controlled hand prostheses. At that age they are more mature and often more consciously motivated for the training. This means that if one does not succeed earlier, one will have new possibilities in the teenages.

CONVENIENT FITTING CONDITIONS

Concerning congenital below elbow "amputations" we have found the most suitable level being within the middle third of the forearm. Then the patient has sufficient stump length to quite easily carry the weight of the prosthesis, and also sufficient place for the passively adjustable rotation module. Besides, the battery can later be put into the socket. In the smallest children we always have to place the battery outside the socket, with a cable in between. In very short and very long stump lengths the patient often has to keep the battery under the clothes, because of the weight or because of the shortage of space inside the socket.

In a 9 years old congenital above elbow amputee we are testing a myoelectric controlled elbow and a hand controlled by the same muscles, but our experience of this is up to now very limited, and no conclusions can be drawn so far.

ROUTINES OF APPLICATION

By the application of myoelectric hand prostheses in children the routine at the Regional Hospital in Örebro has been as follows:

At the patient's first visit the EMG from the stump muscles are examined after being recorded by means of skin electrodes. In this connection the electrode sites over the flexor and the extensor muscles are thoroughly indicated and transferred to the plast cast which is being made the same day. Furthermore the muscle force in different muscle groups is recorded, and measures of different lengths and circumferences are taken from both upper extremities. If possible, recordings of temperature and sensibility conditions of the stump skin is made on the same occasion. At the first visit we also make a general assessment of the child, and even of the parents' suitability from the actual point of view. Perhaps the most important point is giving adequate and comprehensive information to the parents, also answering their various questions. On this first occasion it is of

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vital importance to spend sufficient time with the family, grounding in a relaxed way the faithful relationship with both patient and parents on which a successful result is based.

We think it is of great importance that both parents are present at the first visit. Even at later visits it is an advantage if both parents are joining the patient, but we do not demand this. Other children in the family are allowed to join if they themselves and their parents so desire.

When the socket is finished and the prosthetic hand mounted, as a rule after some week, the total prosthesis is fitted and eventually adjusted, and then training is started very smoothly. Depending on the distance to the home, the patient is returning for trying the inner socket and later the total prosthesis, or the patient and one of the parents are staying all the time at once at the patients hotel quite near the hospital. During the training period, 1 - 2 weeks, they are visiting the hospital for training and investigations 2 - 4 times every day. The socket is controlled by us and smaller adjustments are made if necessary. We also make sure that the child can manage and that the parents are able to cope with the putting on and the maintenance of the prosthesis before they return to their home.

As far as our experience goes there should not be too many people around the child at the examinations and during the training. However, apart from the parents at least one of the staff should be following the child all the time and be the link between the patient and the different other parts of the involved staff.

When the patient and the parents have returned to their home we want a telephone report after a couple of days. Even later it is important that the parents feel that they whenever they want may call someone of the prosthetic team, to discuss smaller or for them perhaps greater problems which may arise. As soon as possible we also try to get a close co-operation with a team or a medical person locally, aiming at a support for the child's training and control by a therapist once a week. Furthermore we recommend a follow up at intervals even by a physician experienced in this field.

Through the reports to the prosthetic team in Örebro from the parents and from the local staff we have been able to gain even more experience, and also to give advices in situations which perhaps are new for the locally involved persons.

ASPECTS OF TRAINING

Training with myoelectric controlled hand prostheses in children is quite different from such training in adults. Even among the children one has to strongly differentiate with regard to the fields of interest in different ages. Within each age group there again will be great individual differences which must be taken into consideration. Even other factors are playing great roles, such as the home conditions, if both parents are working outside the home or not, the parents' type of personality and their attitudes, the interest and capability of the staff at the nursery school etc, the distance to an occupational or physical therapist, the ability and experience of the orthopedic workshop, etc.

Also concerning the information and the guidance of the parents such conditions must be taken into consideration.

The principle of training pre-school children is to use toys and activities suitable for the actual age group, also taking in regard the degree of maturation, the type of personality and the temper of the individual child. In co-operation with the parents one has to find activities awakening the child's interest and pleasure, at the same time as much as possible making it necessary to use both hands or otherwise giving the child the possibility of detecting advantages of using the prosthesis. The prosthetic training should never be done with any kind of compulsion. Especially in the first stages it is also contraindicated to extend the separate training period too far. On this point the personal experience of the therapist is of great importance. The child must not feel the training as stressing, this certainly will decrease the interest. One has to remember that the concentration span of a child is very limited.

One also has to be aware of the suitability of the socket. It has to be adjusted or a new socket be made if the child is demonstrating pain reactions or other signs of difficulties from the socket. It is also important always to examine the skin when removing the prosthesis. With strong skin irritation socket adjustments have to be done, eventually one is forced to make a pause in the prosthetic training, until the skin reaction has gone.

On the first training occasion both electrode amplifiers ought to be set on maximum, until the child begins to detect how she herself is causing the opening and closing of the prosthetic hand. In the somewhat older pre-school children the amplifying successively should be slightly decreased, the opening of the prosthesis always being somewhat more difficult to bring about than the closing. This is to avoid the hand being kept in an open position during walking etc, and to avoid that the child unwillingly loses things which she is carrying in the prosthetic hand.

The youngest children may sometimes feel the spontaneous opening and closing of the hand as unpleasant and eventually even frightening. The battery then ought to be put off most of the time, the child only being trained to accept the socket and the weight of the prosthesis. When the battery is put on and spontaneous opening movements are going on, the parents must be very carefully looking after the child and in a smooth way keep its normal hand away from fastening in the prosthetic grip.

DISCUSSION AND CONCLUSIONS

It ought to be said that the children being born without one hand and part of the forearm usually do manage very well in their future even without any type of prosthesis. Many adults and even children in this situation prefer to manage in daily life without any prosthesis, perhaps wearing such ones for special occasions and of cosmetic reasons. The advantage of doing things without a prosthesis is that one has the possibility of getting useful feedback information from skin sensibility, at the same time perhaps making use of the stump length and maybe even wrist movements. The disadvantage is the asymmetry of the body, which often leads to pains in the neck, the back and/or the shoulder regions. Besides, an active prosthesis may give the patient more possibilities by addition of the grip function.

Of course it is difficult without a proper examination to tell more definitively what can or can not be done in the individual case. Apart from the length and other conditions of the forearm stump there is the need for adequate training and follow up, one must have possibilities of adjustments and repairs of the prosthetic hand, etc. Of that reason it will be necessary for the patients to be taken care of in their own country. In England the Health Department expert team, with which we are closely co-operating, is now building up the organization to meet the different special demands. It would be a great advantage if the same could come true in other countries where supplying pre-school children with myoelectric hand prostheses is planned to start.

One should always remember that the parents are perhaps the most important part of the team around the patient, and that they before the trial is started should be very thoroughly informed. They should also be told about the possible difficulties and be prepared to meet the unavoidable breakdowns which will occur more or less often. Besides, it is motivated to remember that especially for the mothers the birth of a dysmelic child is a shocking experience, and that there is a great need of taking care of the parents as soon as possible, discussing in an adequate way the whole situation, the common feeling of guilt, the child's possibilities in the future etc. It should also be remembered that every type of prosthesis is only a tool, and that it never can be like a normal hand, which people sometimes seem to be thinking.

The experience gained by the prosthetic team in Örebro during this 7 years, in children from different parts of Sweden and also from Norway, has strongly supported our opinion that early application of myoelectric controlled hand prostheses ought to be tried where there are no contraindications. Of course we do not know yet how these children will behave later, how they look upon their prostheses and how they use them when they achieve adult age. What we have seen, however, is that there is a much better acceptance of the myoelectric controlled hand prosthesis in pre-school children compared to adults.

In general the children have very soon been able to control the myoelectric hand prosthesis in an adequate way. By very early applications there obviously are great possibilities that this prosthesis relatively soon will be integrated in the normal psychomotoric development and be felt as part of the body.

The main point in the work with prosthetic devices in children should always be to aim at the very best practical as well as psychological benefit for the individual.

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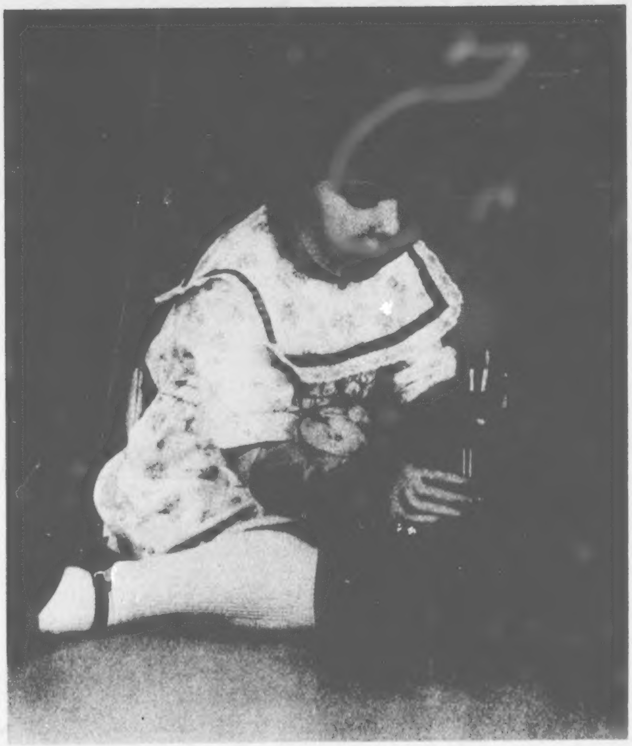
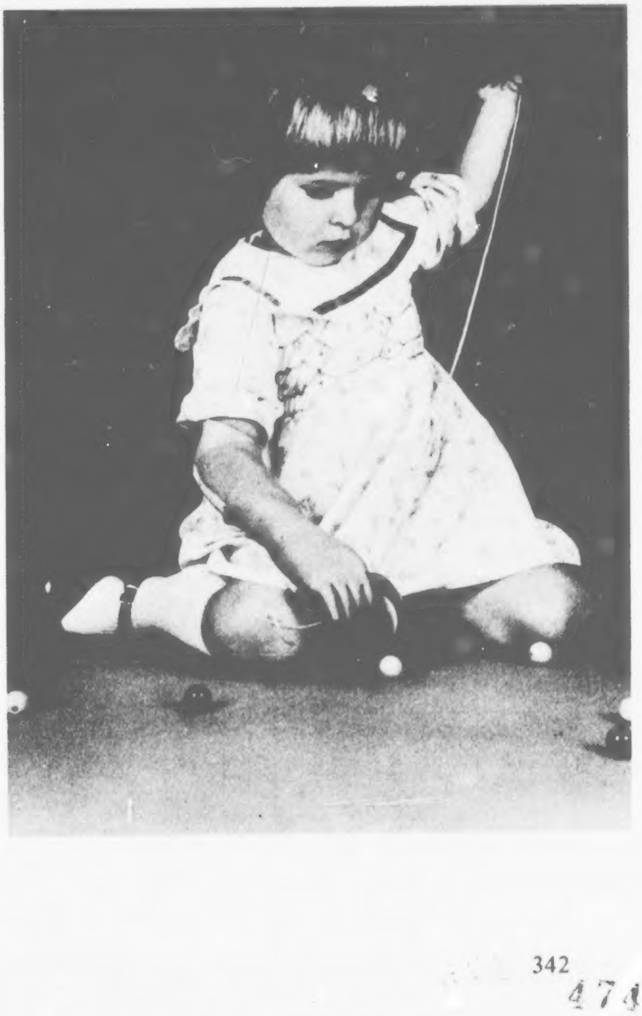


Text to the pictures:

A 3 years old girl during training activity with her new myoelectric controlled hand prosthesis.



UTILITY OF A COMMUNICATION AID TO COMPREHENSION AND CO-OPERATION IN FAMILY LIFE AND THE TRIALS AND TRIBULATIONS OF ITS COMMERCIAL MANUFACTURE

O.I. Butler and J.F. Fouldes†

ABSTRACT

The paper discusses the conception, formulation, research, development and field trials of a Typing Aid, Remote Controlled (TARC) for the physically disabled. An account is given of the construction of TARC with its built-in safeguards against uncontrollable maloperation, which permits an effective degree of communication by persons who are otherwise completely communicationless; as well as its therapeutic value which can be usefully enhanced by family co-operation. Further, an account is given of the successive difficulties and delays encountered over a period of twelve years in progressing from the 1966 prototype to commerical manufacture of a quite simple device, in order that other workers in the field may be aware of, and benefit from, this experience.

INTRODUCTION

In mid-1965, the authors were asked by Mr. J.H. Fortescue, Headmaster of the Chantrey School for Cerebral Palsied Children, Sheffield, if they could devise some form of inexpensive equipment to allow one of his severely handicapped pupils to operate an electric typewriter. The pupil could neither walk, talk, write nor operate satisfactorily any of the available but highly-expensive U.K. and overseas communication aids; mainly due to the uncontrollable movement of his limbs and body. The possibility of modifying available communication aids was examined by the authors, with no useful result.

However, the exercise indicated the possibility of a different approach to the problem. With this in mind, the authors formed a small committee comprising members of Sheffield and London Universities actively engaged externally as Consultants in Psychology, Education, and Engineering, together with representatives from the Spastics Society and engineering industry. That is, members with considerable experience in the wide range of severity of affliction among the physically handicapped, as well as those fully acquainted with engineering developments and manufacturing techniques, to permit an intensive study of the problems of communication and associated ergonomics.

The study resulted in the Committee recommending that the aid should be such as to
(a) encourage its ready acceptance by minimising its departure from a normal means of communication,
(b) be of therapeutic value by developing in the user the skill and desire to dispense with the aid, and
(c) provide a basis on which both school-leavers and adults could be trained to enter various vocations, and thereby integrate more readily into their family circle.

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Included among the possible devices considered by the Committee was
(i) a redesign of the electric typewriter which incorporated the aid as an integral unit,
(ii) the use of solenoids in a semi-circular and inclined array to type characters on movable paper tape, and
(iii) a teleprinter arrangement with a maximum of seven solenoids to print dots and/or horizontal and vertical lines, to build up the required characters of normal and even larger dimensions.

However, it was decided to use a standard typewriter, in order to minimise the development period of the aid, together with a robust separate and larger keyboard having the same layout of keys as the typewriter. This, with the facility of mounting the separate keyboard directly over the typewriter, was regarded as most likely to satisfy the above recommendations for almost all forms of physical disability.

PROTOTYPE TARC

For the purpose of proving the feasibility of a simple and inexpensive communication aid, it was decided that the separate keyboard of the prototype should include only those facilities available on the actual typewriter which were regarded as essential for the basic education of a very young person. A final decision on the conflicting requirements of maximum facilities and minimum cost could be taken in the light of subsequent experience with the prototype model.

In devising, constructing and laboratory testing the prototype model within approximately six months of the Committee completing its deliberations, it was necessary to improvise with a majority of 'home-made' components using materials readily available in the University Engineering Departments. The time restriction was imposed by the period of availability of a final-year student in completing the task as the last of his B.Eng. projects. Fortunately, it provided excellent training in using physical laws, metals and other materials to the best advantage in devising shapes and configurations to perform precisely determined functions, as well as valuable experience in unambiguous communication by drawings and instructions to workshop personnel.

The prototype was installed at Chantrey School for actual field trials in mid-1966. It is still in use in the school. It has demonstrated its capability of fully satisfying the Committee's recommendations, as well as providing ample information for the improvement of subsequent models. Fig.1 shows the prototype model being operated by the pupil for whom it was devised originally.

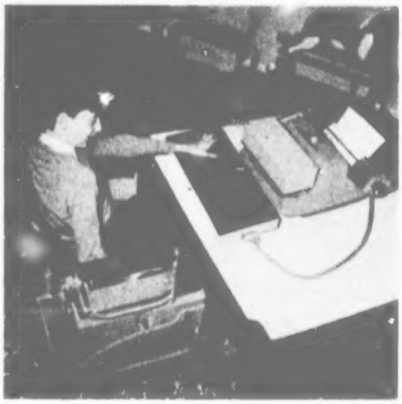
Fig.1 Prototype TARC

BASIC ASSEMBLY

The prototype and all later models of TARC consist of three basic parts. Firstly, the separate keyboard with its enlarged characters distributed in correspondence with the typewriter keyboard. Secondly, an electric-pulse generator whose time-function can be varied to suit the proficiency of the user. Thirdly, an electromagnetic actuator block which operates on the same character of the typewriter as that depressed on the separate keyboard.

The actuator block is mounted directly onto the typewriter keyboard, whilst the generator is housed in the separate keyboard as an integral unit. The latter can be little different in size from the typewriter keyboard and located directly above the actuator block, to encourage the feeling that the user is operating a normal typewriter. Alternatively, the separate keyboard can be located at any angle on, or away from, the typewriter to suit any constraint on the position of the user.

INHERENT CORRECTIVE FEATURES

The inherent corrective features include the prevention of:

(1) undesired operation with slumping of the user on to the separate keyboard,
(2) damage due to prolonged depression of any one or more keys,
(3) unwanted repitition of typing of the same symbol due to uncontrollable shaking of the user,
(4) operation of unwanted keys whilst the wanted key is depressed,
(5) simultaneous operation of two or more keys,
(6) damage due to excessive pressure on any key and,
(7) maloperation due to salivation.

The successive features are obtained by (1) the simple expedient of recessing the keys below the surface of the separate keyboard; (2) arranging for an initial short-duration pulse of current to operate the actuator block with depression of the chosen key, after which the circuit remains "dead" until the key is fully released; (3) and (4) providing a time-delay in the pulse circuit which functions to suppress further operation of all keys, after the initial pulse has occurred with the first depression of the wanted key; (5) ensuring that sharing of the initial pulse by more than one key fails to provide any key with sufficient operating current; (6) providing robust mechanical "stops" to the keys in the separate keyboard; and (7) inserting a water-proof sheath between the keys and switches of the separate keyboard.

ACTUATOR BLOCK

Continuous classroom experience with TARC since 1966 has been primarily responsible for successive improvements in the keyboard, overall circuit and components. However, its initial major disadvantage, in common with similar devices which have been manufactured in the U.K. and abroad, has been the difficulty of viewing the typed output directly as it appears on the paper sheet, with the user and typewriter in their normal and most convenient relative positions.

Despite using solenoids of the best available U.K. designs, the depth of the actuator was excessive in providing the required force and travel of the armatures, to the extent that it seriously impeded vision of the typed output. Various possibilities of indirect viewing were considered, and rejected because of their cost and added complexity. A survey was carried out of new computing, data-processing and information-handling systems, with no success in discovering improved solenoid designs. The problem was presented to the foremost solenoid specialists abroad, on responsible advice, with the same result.

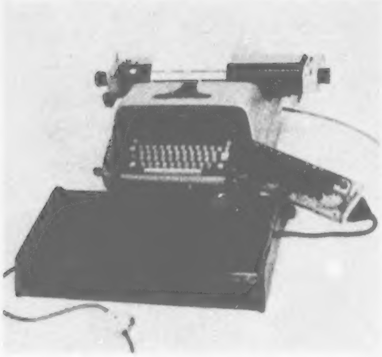

Fig.2 Opened-up view

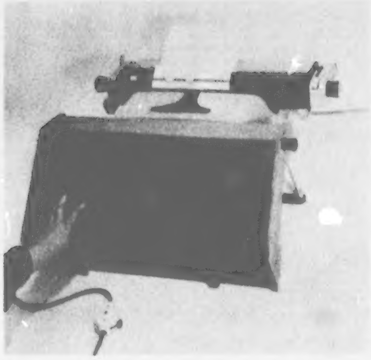

Fig.3 Penultimate model

Fortunately, a reappraisal of some decades of teaching, research and industrial experience of the authors in electromechanical energy conversion indicated an extremely simple solution. It utilises the dual forces of electromagnetic attraction and repulsion from a composite armature, reduces the height of the actuator block by quite 50%, and facilitates encapsulation of the block, as shown in Fig.2. The new solenoid has been patented by the authors for its general industrial application. It provides a "slimline" actuator block to allow full vision of the typing as it proceeds (cf. Figs.1 and 3).

COMMERCIAL MANUFACTURE

It is relevant to comment on the difficulties encountered in obtaining the satisfactory commercial manufacture of such a simple device as TARC, particularly in view of its extending over a period of twelve years. In all, a total of twelve manufacturers have been involved during this period. The first manufacturer, located in a London suburb, was highly recommended by a large Government establishment on the basis of previous direct contact. Slow progress was made for approximately a year when internal discord resulted in the departure of some executives; among them being the one who had been responsible for most progress, and who persuaded the authors to leave the project with him whilst he built his own Company. Quite two years elapsed before the manufacture of a specimen TARC. To the authors' dismay, it was virtually a copy of the prototype with little effort to properly 'engineer' the final product beyond the original 'mock-up'. Also, general business and unfortunate health problems necessitated a search for a new manufacturer.

Preliminary correspondence for some months resulted in a meeting with the chief executive of a Yorkshire company. We were advised that manufacture was dependent on the authors accepting a substantial part of the selling price, in line with others, and not being further concerned with the product however 'engineered' and reliable. The authors declined. Of several possible manufacturers in Sheffield, three were seriously and successively involved in extensive discussions. The first concluded that his facilities were inadequate. Reluctantly, the authors had to conclude themselves that the remaining two were insufficiently equipped to manufacture an acceptable TARC.

The seventh definite involvement was with a Derbyshire company. A liaison of eighteen months to 1972 was very promising. However, unexplained delays then occurred and, after a further year, the company went into liquidation due to general mismanagement. It was now evident, before seeking the eighth manufacturer, that it was necessary for the authors themselves to 'engineer' the product; i.e., solve the relevant problems of manufacturing techniques, make the maximum use of standard components, coordinate industrial assembly and redesign the external appearance whilst ensuring the least first and maintenance costs of TARC.

In 1974, it was arranged for a further Derbyshire company to manufacture TARC and for it to be marketed by another company. The arrangement ended after eighteen months with the manufacturer being absorbed by a larger company interested exclusively in mass-produced electronic components. A still further Derbyshire company expressed a keen interest in manufacturing TARC, with an offer of Board Directorships for the authors to collaborate in other proposed ventures. Enquiries into the financial, managerial and other resources of the company indicated its early demise. Subsequent liquidation confirmed the decision of the authors to decline amicably the possible ninth manufacturer.

Our possible tenth and eleventh local manufacturers were given much technical advice and a great deal of the authors' time for over a year of serious endeavour. Much of the advice was so elementary, and the time so excessive, as to show clearly that neither could be depended upon to manufacture a reliable TARC. The tenth manufacturer retired gracefully, and the eleventh with reluctance until it was stressed that non-voluntary commitments prevented the authors giving further advice and time. It should be added that our trials and tribulations have been increased by the inherent difficulties of some typewriter manufacturers to sustain the production of certain of their models well-suited and particularly envisaged for use with TARC, in view of their moderate cost.

It is pleasing to record that many industrialists have been extremely sympathetic and helpful in advancing the project. It is especially pleasing to report that within the past year an organisation has been located with whom an amicable collaboration has been established, with every likelihood of being maintained. It is anticipated that a commercial model of TARC will be available in September, 1978. A penultimate model, constructed by the authors, is shown in Fig.3 with the keyboard at one of its possible positions, including the horizontal.

COST AND THERAPEUTIC VALUE

A major goal has been to minimise the cost of TARC plus typewriter to within a family's financial resources, in case of outside help being unavailable, and thereby avoid vegetation and difficulties in family co-operation of a young person leaving school or college and its facilities. In this connection, the making of moulds, the checking of the properties of plastics, the sifting of manufacturers price lists and performance data on components, and many other aspects have been laborious and time consuming, but rewarding.

A further major goal has been to develop a means of communication which differed to the least possible extent to that used by the non-handicapped. This ruled out the use of any coded device. In any case, the latter tends to be excluded as far as the cerebral palsied are concerned, due to their greater difficulty in maintaining the necessary degree of concentration. In addition, despite the large keyboard, its development as a simple and compact arrangement was desirable to give the feeling that one was using little more than a normal typewriter.

It was hoped that such a minimum departure from a normal means of communication would encourage its acceptance and, gradually, help to develop in the user the skill and desire to dispense with TARC. It has been gratifying to find that the possible therapeutic value of TARC indicated by the user of the first model has now been confirmed by others.

It should be stressed, from the experience of the authors, that the dedicated patience, guidance and expertise of teachers of the physically handicapped are always the main reasons for any therapeutic results. TARC is merely a simple tool in assisting such attributes, and will necessarily remain the minor contribution.

CONCLUSIONS

A simple device has been developed which has been shown by extensive field trials to satisfy criteria formulated by an informed committee regarding the provision of a low-cost means of communication for the physically handicapped. Its other chief virtues are its built-in safeguards against uncontrollable maloperation, its encapsulated slimline actuator block to allow full vision of typing, a minimum of components, constructional simplicity and therapeutic value.

ACKNOWLEDGEMENTS

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INTEGRATING THE DISABLED WITHIN THE COMMUNITY : THE HONG KONG APPROACH

IAN ROBERT STRACHAN

ABSTRACT

Although rehabilitation services began in Hong Kong a a century ago, major developments have occurred since 1945, culminating in a White Paper published last year. The policy is to provide a co-ordinated multi-disciplinary range of services and thus to integrate disabled people within the community. Special education services are well established, except in respect to the mentally retarded - expansion will be concentrated on them over the next decade. Until full provision is available support services to parents will be increased. The need for general support for families with severely disabled children is recognised. Community care will be expanded as will residential care within the community. Pre-school care is an area where more must be done to integrate disabled and able-bodied children. Improved vocational training courses and a centralised employment service will assist more disabled people find jobs. Access and transport remain problematical in our crowded city.

Principal Assistant Secretary for Social Services, Hong Kong Government.

INTRODUCTION

Rehabilitation services have a long history in Hong Kong. The first home for the blind was built in 1863 and the first school for deaf children opened in 1935. However the most significant developments have occurred since 1945. Para-medical care was established in the late 1940s and social work counselling for disabled people in 1954. During the 1950s sheltered workshops, training centres and recreation and social clubs were established for the physically handicapped, the blind and the mentally handicapped.

2. Special education began in 1960 as a separate service within our education system. Gradually a network of special classes and schools has been built up. Screening programmes in primary schools to detect disabilities commenced in 1967. Our first medical rehabilitation centre opened in 1962 and our first hospital for the severely mentally retarded in 1972.

3. The voluntary sector has been at the forefront of these developments. It has been estimated that 70% of direct provision of rehabilitation services is through the more than 90 agencies in the voluntary sector. Government subventions have of course increased dramatically in recent years. For example Government support to agencies involved in special education and social rehabilitation this year is about six million pounds, an increase in support over 1977 of 50%.

4. In the early 1970s the Hong Kong Government took the view that our development in rehabilitation had reached the stage where we should re-examine our priorities and objectives. So in 1974 a working group of Government departments and voluntary agencies was set up to plan a co-ordinated and integrated approach in rehabilitation. We followed a standard programme planning process with formally defined stages : what areas should be covered; what are or should be the policy objectives; who will require services and what are their needs; what is currently being provided and thus what are the shortfalls in provision, having identified these, what options do we have to meet the shortfalls and what are the financial and other consequences in planning additional and new services; and finally which options should we choose and in what degree of priority.

5. This process has radically altered our thinking. In particular we have learnt to work as a team not only among the various professionals and administrators but also to involve disabled people in our discussions. Hong Kong is a relatively small place with only four and a half million people, only 400 square miles in size and with an economy at present growing fast enough to take on board a faster rate of social development. But our experience

may be of interest to other territories who have yet to develop overall planning and management machinery for rehabilitation, and in particular our neighbours in the Asia and Pacific region.

6. We completed our first rehabilitation programme plan in 1976 and in October 1977 published a White Paper stating Government's policies for the provision and expansion of rehabilitation services over the next decade. The White Paper was entitled "Integrating the Disabled into the Community : A United Effort". This afternoon I would like to demonstrate that integration is not really possible without the united support of all those involved in rehabilitation. The 1978 Review of our plan has just been completed and I would like to highlight those areas which deal with the integration of the disabled person within his family and the community.

PRE-SCHOOL TRAINING AND CARE

7. In April 1978 we commenced a major developmental screening programme which by 1981 will be extended to all Government maternal and child health clinics. This programme encourages parents to bring their children to their local clinic to observe the child's general development during the first five years of his life. Those identified with disabilities will be referred for treatment and training. This training is consciously planned to involve the parent so that programmes instituted by the professional worker can be repeated in the home environment. The screening programme is being given wide publicity. It is provided without charge and it is hoped that the majority of families will follow through the whole programme. At present only 20% of families have responded to existing programmes. In 1979 we plan to use Health Visitors attached to clinics to follow up with home visits to mothers who cannot or will not attend the screening sessions and where appointment reminders have not had the desired effect.

8. In addition screening programmes for primary school children to identify those with sight, speech or hearing defects, and those who have behavioural or learning difficulties are being expanded. Again remedial services are being provided through multi-disciplinary special education centres and the parents' involvement in these programmes is an intrinsic component.

9. It will be some years yet before we have full provision of these services. In particular pre-school care and training falls far short of known demand for many disabilities. But at least our programme planning process has helped us to identify the size of this problem : what we must now do is to meet the demonstrated demand.

10. We are conscious that if we do not identify the very

young disabled their problems will be exacerbated later on. And if we do not provide sufficient training and education for these young children, parents will be discouraged and pressure will grow on Government to place their children in institutions because the burdens are too heavy for the family to bear.

11. Our general approach to pre-school care for disabled children over two years of age is to integrate the less severely disabled into ordinary child care centres. This we are now doing and the programme will be expanded. But we realise that the staff in such centres need special advice, support and in-service training. This we plan to offer from 1979. For the severely disabled we do not propose an integration policy. Instead we will commence in 1979 to expand provision of special care centres aimed specifically at the 2 to 3 age group. A small number of such centres already exist and mothers are encouraged to accompany their children as often as possible. This trend will continue.

SPECIAL EDUCATION

12. In planning our special education services we intend to integrate as many disabled children as is feasible within the ordinary school system. The objective is to provide nine years of free general education for disabled children, as we provide for non-disabled children. Thus places for those who have partial hearing, sight or physical disability are being expanded in ordinary schools. In respect of the blind, the profoundly deaf, the severely physically handicapped and the mentally handicapped, special schools are being provided. Children enter at the age of 4 whereas the the non-disabled do not commence school until they are aged 6. Having received special education in primary schools many disabled children can and will be integrated into ordinary secondary schools.

13. Naturally the teacher : student ratio in special education is more generous than in ordinary schools and indeed we are trying to adopt the standards provided in developed countries. We are looking at how best to expand multi-disciplinary care within special schools so that the teacher and the parent can draw on the resources of the social worker, the therapist, the psychologist, the psychiatrist, nurses and visiting doctors. We are also expanding the provision of peripatetic and resource teachers. This is especially so for disabled children integrated within the ordinary school system. For example, we plan to provide in 1979 resource teachers for blind students who are integrated into the higher forms of ordinary schools and peripatetic teaching services for deaf students integrated into ordinary schools.

14. Our provision of special education for disabled children is now fairly comprehensive except in respect of the mentally

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handicapped. Over the next decade this will be a priority area of expansion and until we have comprehensive coverage many mentally handiapped children will not receive the education we want to provide for them. Thus we are looking at ways in which we can support families outside the school setting. Parents whose children are not attending schools will be encouraged to register with their local special school and discuss mutual problems with teachers and social workers. A new scheme using volunteers to look after children while parents attend to other home duties will be launched in 1979. The multi-disciplinary team approach is well recognised and how best to provide this is one of our major concerns at present. The major constraint is a lack of manpower especially in the areas of psychiatry, educational psychology and physio, occupational and speech therapy. Local training programmes are being expanded as quickly as possible but it will be the mid1980s at least before we have sufficient trained manpower.

15. Before I leave the subject of children let me touch briefly on the Chinese family. Traditionally it is a tightly knit unit which extends in varying degrees to a wide coverage of blood relatives. Thus it is natural that a disabled child should be cared for within his family. The compactness of Hong Kong contributes towards this spirit of family help. But we recognise the general pressures in Hong Kong towards more nuclear families when industrialization and urban living encourage many mothers to work, environmental constraints entail small living units, and the growth of social and leisure activities take the family away from home more often. With a disabled child in a family the problems are accentuated. Conscious of these trends our provision of services must sustain the family where love, care and the development of the disabled child can be manifested most effectively.

THE DISABLED ADULT

16. Now let me turn to the adult disabled. As we expand education provision it will be possible to place disabled people in much better jobs in which their potential will be more adequately fulfilled. As in many developing countries, vocational training for the handicapped is the responsibility in Hong Kong of the social worker. But we recognise that this is more properly an educational role. So over the next four years the Education Department will gradually assume responsibility for this training. The emphasis will be to integrate as many disabled people as possible within ordinary technical institutes, apprenticeship and other training schemes and the Polytechnic. For the severely disabled, special vocational training centres will be provided. We will also be examining how to fuse into these services people who are disabled in adult life through accidents etc. and in particular how to co-ordinate medical and vocational rehabilitation. Re-training of able-bodied

adults is a common feature in the developed world but is uncommon in territories such as Hong Kong where industrial training programmes are less advanced. Nevertheless a need to retrain some disabled adults is recognised and a start has been made.

17. Placing disabled people in open employment is at present a task for social workers in Hong Kong. Next year the Labour Department will begin to take over responsibility for a centralised employment service so that disabled people receive the same professional standards of service which we provide for the able-bodied.

18. Those of you who have been to Hong Kong will recognise that housing is our most difficult social problem. Our population has increased more than seven times since 1946. For the adult disabled the problem is accentuated. They often find themselves at the end of the very long queue for adequate housing. Thus we are charting out specific areas of provision for them. Let me give just one example. Surveys in our psychiatric hospitals reveal that about one-third or about 700 in-patients, who do not have an adequate home environment to return to, could be discharged to care within the community. We already have half-way houses for the discharged mentally ill. But we now plan to expand community care by providing two new services, that is long-stay nursing homes and boarding houses. This will permit at least 1400 discharged mentally ill people to live within the community as we expand this provision over the next ten years.

19. Another very vulnerable group are disabled people who live on their own and we are examining how to integrate them within our public housing programmes.

20. Many disabled people face daily problems of access and transport. We have a voluntary Code of Building Practice. Physical access is being improved and in particular in public housing progress is being made. Special programmes are in hand to improve facilities on public transport, for those who own and drive cars, and for the severely disabled. In respect to this latter group a minibus scheme was launched in May 1977 by a voluntary agency with the help of a grant from the Government to encourage the more severely disabled to get to work, visit clinics and participate more fully in social and recreational activities. But we recognise that much more must be done to encourage mobility given the constraints of our crowded city.

CONCLUSIONS

21. Care in the community is not cheap. It is also complex since the infrastructure of services must constantly be added to. For example in 1979 we hope to establish an advice centre for the adult deaf, many of whom are over 60 years of age. Visiting people in their homes will be an area of growth. We plan to expand what it is at present a small experimental scheme of community psychiatric nursing next year. We also recognise the need to increase community physio and occupational therapy but sadly recognise that we do not even have

enough staff to man our hospitals and clinics properly. So this will be something for the early 1980s when more locally trained professionals are available.

22. Finally there is the general public. They need to be convinced of the values of integrating disabled people with themselves. We are already using some of our resources such as Educational Television social studies programmes, local documentaries and so on. I do not believe the war has yet been won in any country but the more integration we attain the more battles against prejudice will be won.

23. We are enthusiastic that we are on the right lines. But we recognise that we have much to learn so that the disabled person can live a full and rich life within his family and the community. We will be spending one week after this Conference visiting various institutions in Britain and hope to return to Hong Kong with further fresh ideas on how to help our disabled people fulfil their potential within their families and the community.

SOCIAL DIAGNOSIS AND PSYCHO-SOCIAL THERAPY IN THE REINSERTION OF HANDICAPPED PEOPLE INTO THE FAMILY LIFE.

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The approach to and the solution of the problems of the handicapped persons have evolved in the course of time depending on the socio-economic and cultural development of our country.

From actions based in the past on charity and compassion, we have reached a stage where handicapped people have a right to rehabilitation and reintegration in our society which has a moral and legal obligation to make available the necessary means. Such obligations are wholly justified by the fact that the same facilities (free education and vocational and professional training, medicare, social security, etc.) are granted to normal persons, the difference consisting only in special schools and possible adjustments of work places for some of the disabled and handicapped people.

Multi- and interdisciplinary research, conducted for over twenty years in our Institute on the rehabilitation of handicapped people, have shown differences in the relative problems of such persons and those of their families, depending on the social-economic development phase of our country, on the technical-scientific advancement in the medical field, on the changes in ideas of and attitudes towards the handicapped and their social reinsertion, as well as on the structural-organisational changes that took place in their rehabilitation.

Such dynamic research works, conducted in the various development stages of our country, approached the problems of disability in all their medical-psycho-social complexity, by classes of handicapped people and by age, sex, type and gravity of condition, recovery prognosis, original geographic and social environment, family situation, educational-cultural life and level of family and handicapped person, etc., in parallel with an analysis of the rehabilitation actions undertaken and their efficiency. An appropiate researc methodology for complex longitudinal studies has been employed over the whole duration of the rehabilitation process of the handicapped studied. Such methods enabled us to know their personal, vocational, family and adjustment to the community problems, the modalities of dealing with them as well as the organisational, institutional and legal needs in the field of rehabilitation.

The findings of these investigations underscored the value of social surveys on family and the productive community both for a thorough knowledge of individual cases from the view point of psycho-social factors determining the handicap and the recommendation of the necessary rehabilitation techniques and psycho-social intervention methods.

The comparative analysis of research conducted separately on the different political and socio-economic development phases of our country, brought out significant differences between the problems of handicapped persons and their families before the II-nd World War and the phases of socialist changes of our economy and social actions of the last 3o years.

So, for example, in the past the family faced difficult problems regarding the care of the handicapped, as there were but few sporadic assistance facilities to this end, which had only a palliative-philantropic character, so that the young and adult disabled were left as passive elements to the exclusive care of their families.

Owing to the low level of the socio-economic development and to the insufficiency of educational and employment opportunities (even for able-bodied people) most young handicapped were uneducated or only with partial elementary education with only a few of them vocationally trained (at low lwvwl skills).

Consequently they couldn't find placement in productive employment and had no personal income. Similar situations were experienced by handicapped people with work induced disability for whom there were no structured social reinsertion actions. Under those circumstances, they led an isolated life of social dependence and were a burden for their close kin causing disorders and disruptions in the life of the family.

The political and socio-economic changes of our country have had significants effects on the solutions for the handicapped people's problems.

Thus, the advancements achieved in the socio-economic and sctientific-technological domains which increased our available means enabled organised and comprehensive actions for the rehabilitation of the handicapped, aiming at their reinsertion in social life. Such actions were supported - and, consequently, made more efficient - by the development of a social solidarity and collective responsibility feelings for the health and the moral well-being of all the citizens of our country.

The rise in the educational and cultural level of our population had an effect also on the attitude towards handicapped people and increased their access to both general education and vocational training. Under the conditions of mandatory general education which includes the whole of our population (and, implicitly, all handicapped persons, too), adequate steps have been taken for training the majority of the handicapped (those with slight functional deficiences) in the general schools together with the normal children, initiating the necessary ergonomic-educational corrections in some individual cases. For those with severe handicaps a network of special schools has been created which ensures their educational and vocational training using such pedagigic methods as are commensurate with the type and gravity of the handicap. This led to a scientific and comprehensive understanding of the problems of the handicapped people and of the extant possibilities for their integration in social life and contributed to a change in the concepts and the attitudes of the community, the family and the handicapped themselves towards illness and rehabilitation.

The advancements of medicine have - by the increase in the efficiency of the medical action - enlarged the number of disabled persons (the epidemiologic longitudihal study includes both the mortality and the disability dynamic structure - by causes and age - and explains the increase in disabled and invalids through reduction in mortality) which led to the need for complex and organized social interventions aimed at dealing with the problems of the handicapped, which the family - involved in the processes of industrialization and urbanization - was no longer able to solve. On the otherhand, the efficiency of rehabilitation medicine improved in many instances the biological disability state thus creating favourable premises for social reinsertion under the conditions of appropiate education and vocational training.

The technical-scientific progress which contributed to the reduction of physical effort and supplied new opportunities for ergonomic improvements of work places, led to an increase in the access of handicapped people to productive employment and contributed to keeping many ill persons in their former jobs by adjusting their workplace so as to ensure the necessary balance bewteen the demands of the job and their psycho-physical capabilities. At the same time, urbanization and the development of villages which paralelled the rapid industrialization rate of all branches created increased work opportunities in the localities where handicapped persons reside which enables them to receive the necessary support from their families in their efforts for vocational and social adjustment.

Also, urban development, through improved housing and social services structured for assuming some of the family tasks (including handicapped persons care) contributed to alleviate the life of the family and - through this - to maintaining a balance in the families with handicapped members which were thus relieved from a series of difficulties in connection with their care.

An important contribution to these improvements was made by outfitting the handicapped with several technical aids designed to facilitate their self-care, their mobility inside and outside their home, and the fulfilling of household tasks, which enabled them to be less dependent on other persons thus avoiding possible discontent and difficulties in their family relations. In this connection we would mention our permanent research concern for a continual improvement in self-care devices and prostheses (we have succeded in designing and producing, in our country, a forearm prosthesis with bio-current) as well as of transport vehicles for locomotor handicapped.

The takinf over by the government of the rehabilitation problems of handicapped people within the framework of social security actions, led to the creation of the necessary conditions for a comprehensive inclusion of the handicapped in a series of complex rehabilitation steps.

In planning the actions aiming at the reintegration in social life of the handicapped, we considered the fact that most of them can benefit by such rehabilitation steps as can ensure for them - from a medical viewpoint: an optimal restoring of their balance that should lead to an increase in their functional capacity and, implictly, in their opportunities for education, training, vocational adjustment and social integration; - froman educational viewpoint - general and vocational training which facilitate an efficient occupational adjustment in such jobs as are commensurate with their psycho-physical capabilities, their aspirations and their personal (and their families) interests; - from a social viewpoint: opportunities to avail themselves of all forms of medical treatment, education, vocational training, employment, vocational adjustment, social security, all of which mean an efficient social integration.

As it follows from an experience of over 2o years of our Institute, the social integration of the handicapped requires the planning of an individual and complex rehabilitation programme, involving medical, educational-vocational and social steps, the effectiveness of which depends on their timely initiation, on their continuity, as well as on the modality of comprehending and solving the problems pertaining to the particular disability condition. The aim of all such steps is to ensure a maximum of:

- autonomy of the handicapped in his or her family, meaning economic independence, development of self-care and capacity for decision making and independent action;

vocational autonomy - meaning the exercise of a socially useful occupation under conditions of productivity comparable to that of normal persons which should provide the handicapped with an income source sufficient for his (her) upkeep;

- environmental autonomy - in the sense of creating the possibilities necessary to enable him (or her) normal relations with members of the community where they live, meaning achieving an adaptation balance between the handicapped person and his (her) setting (family, school, work-team, community),which depends on both the handicapped and members of his or her environment.

On the basis of such a philosophy, the rehabilitation of the work capacity of handicapped persons has acquired new dimensions in our country in the sense that the steps undertaken are no longer reduced to a "blind rehabilitation" which should only aim at a general functional adjustment to exercise. Such actions are organized and structured so as to correspond to the particular features of the handicapped. Thus, the actions aimed at the biological restoration are subordinated (and complementary) to those connected with education and vocational training, placement in productive employment and adequate adjustment to work and integration into family and community life.

For these reasons, the "custom-tailored" work capacity rehabilitation programme is based on a scientific assessment of the emotional and physical capabilities of the handicapped (evaluated also from the angle of disabiliy prognosis and possible compensations) which should match the biological and social demands of the general educational as well as the work-load of his or her occupational activities.

Depending on this correlation, a rehabilitation program is worked out and attitudes are shaped, so that there are steps recommended for those diminished in their biologic-social capabilities which can be corrected with medical means or ergonomic training and adjustments at the working place and in social life and a different set of recommendations for those whose disabilities cause important social integration disorders that can only be dealt with thrpugh special steps.

Rehabilitation steps must be deployed so as to fit smoothly into a larger programme worked out by a complex team. In this connection, in the rehabilitation of the young handicapped (child or teenager) the aim pursued is that of creating the physical, emotional and social conditions which should enable the individual to develop along the lines of an efficient general and occupational education and training. This, in turn, would make him or her capable of acquiring the necessary skills for the later exercise of an occupational activity, under conditions of organic balance, with a productivity comparable to that of normal persons doing the same job, and which should enable him or her a balanced integration in the work-team, the founding of a family, and an active participation (within the limits of the possible) to community life. The rehabilitation of the adult handicapped is aimed at restoring the physical, emotional and social capabilities for maintaining or recovering the possibilities necessary for useful and productive employment which should permit him or her an occupational, familial and social reinsertion.

As it results from the findings of our studies, the above mentioned steps had a positive effect on the rehabilitation of physically handicapped persons who had had the benefit of medical treatment and general and vocational training and were employed in industrial jobs congruent with their psycho-physical capacity, as well as with their interests and aspirations.

Thus, as it results from a longitudinal study, concerning the social integration of the graduates of special vocational training for loco-motor, visual and hearing handicapped (931 cases), over a period of 5 years[1] and followed up 2-5 years after completion of their studies, 90% of them (predominantly loco-motor handicapped and hearing impaired) achieved very good positions, comparable to those of their valid workmates, (most of them) founded their own families and led a normal family and social life. Vocational adjustment difficulties found with the other 10% of the graduates (a similar percentage was found also with the graduates from normal vocational schools) were due to errors in vocational guidance, lack of continuity in the rehabilitation program and, particularly, to the insufficiency of social actions and services upon and after their placement.

At the same time, their improved status was also due to the extant prophylactic steps such as: changes in the workplace and arrangements aimed at optimizing the relation man-work place, the creation of opportunities for part-time jobs for persons with reduced work capacity and, for psychic handicapped, employment in repetitive, simple jobs with a minimum of intelectual demands. Under such circumstances handicapped people become active persons participating to family income and life with a changed status in family and society.

In this respect our studies underscore the value of increased accessibility of the handicapped to complex rehabilitation facilities, of the cost-free character (or minimal contribution by the family) of such facilities, and, particularly of the example of individual cases of socially integrated handicapped persons which increased the confidence and the interest of the families, and the number of applications addressed to rehabilitation services. Also noteworthy is the growing aspirationsof the family in connection with the social future of the handicapped and their stimulating effect on the efficiency of social integration. We would also mention the efficiency of our social policy in maintaining a permanent relation between the family and its handicapped member by the creation of special privileges for the relative families such as: additional housing space, priority on the housing list and the use of social services, motor vehicles for loco-motor handicapped, free transportation of accompanying persons during rehabilitation period, etc.

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[1] Meaning five succesive series of graduates.

The application of last year's law by virtue of which all III-rd degree handicapped and disabled persons of the social security were placed in productive employment - a humanitarian and social well organized action - demonstrated the value of the concept of reinsertion into social life of this category who, as it follows from our follow-up studies, have adjusted to work, have restored balance in their families life where the disability caused economic shortcomings and relationship conflicts, recovering at the same time a feeling of usefulness and human dignity as active participants to the social and productive life of our country.

The study of community and family behaviour proves - on the basis of statistical data from a representative sample - that where public opinion and social legislation take positive action (individual dealing of cases) the application of psycho-social methods takes place under easier circumstances, and the number of cases calling for special treatment diminishes.

Our studies revealed, at the same time, that occupational adjustment and integration in the micro- and macrocommunity of handicapped persons is facilitated wherever those concerned with rehabilitation include in their preoccupations also the problems of preparing the handicapped for integration into social life along with normal persons and where such concerns are considered ever since the initial general and vocational training phase.

Our surveys also revealed that occupational adjustment and social integration are influenced wherever the handicapped are supported by their work-teams and their families for successfully dealing with the difficulties which might arise during the adaptatio period. However, such support depends particularly on the degree of information of the work-team and the families on the capabilities and limits of the handicapped person as well as on the availability of adequate social services for solving housing, personal care, household chores, leisure time problems and for rising the level of general clture and occupational training of the handicapped.

INTEGRATION OF THE PHYSICALLY HANDCAPPED CHILD IN THE FAMILY AND COMMUNITY IN A DEVELOPING COUNTRY

M. Graça Andrada[*] ; Antónia Goulão[**]

I - INTRODUCTION:

The aim of rehabilitation is, not only developing each child's potentialities, correcting deformities or deficiencies and stimulating their abilities, but also promoting his integration in family, school and community.

In order to achieve this aim it is essential to make an early diagnosis and early treatment with parents guidance and support.

Child development depends on one hand upon his own skills and on the other hand upon his environment.

As a rule we find a higher incidence of handicapped children in families with poor socio-economical background.

In a country such as ours, where the socio-economical conditions, health and education are still adverse for all children, we are faced with great problems regarding the rehabilitation of our handicapped children.

We believe that integration is very important but we are faced with many problems due to poor housing conditions, low socio-economical status and poor educational background.

The purpose of our work is to analyse the situation of our contry regardin general health, socio-economical and educational problems, studying the main dificulties towards integration of the handicapped children admitted to our Unit in 1976-77 and making some conclusions as guide lines for the future.

II - GENERAL CONDITIONS OF THE COUNTRY

Portugal, (mainland and islands) has a surface of 92.082 square Km and a population of 9.448.000 inhabitants (demographic statistics 1975).

In spite of an improvement, in the way of living of our population during the last few years, we still have one of the lowest percapite incomes of Europe.

Housing, public health, feeding and transportation are still very inadequate specially outside the main cities and even in these.

Regarding education although we have obligatory education (only 6 years but will be increasing to 8 years very soon) there is still a very high rate of illiteracy. In the 1970 census only 33% of the population knew how to read and only 0,5% had university studies.

Many villages have no school and access to the nearest school is very hard even for normal children.

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Although the number of pupils in each class should be limited to 30, sometimes it reaches 40 children, all groups of primary education being with the same teacher.

The basic training and background of our teachers is still of very low standard, although the programme of their training has improved very much lately.

There is a great obscurantism of the population and religious influence and so, deficiencies are considered predestination or God's punishment, accepted as misfortune and looked upon with pity,waiting with resignation for the miracle.

Regarding health, altough there is already a system of social security, covering by law, almost all the population, the existing services are very inefficient and do not respond to the needs of our population.

The basis of a National Health Service is already planned by the Government, this service covering all social classes with preventive, curative and rehabilitation medicine is going to start very soon although only in a few districts at experimental basis.

Now, medical assistance is concentrated in urban Centres. Doctors and paramedical professions besides being insufficient in number, are mainly badly distributed.

The number of doctors in 1975 was 1/851 inhabitants, therefore not very low (Sweden 1975 1/533 inhabitants) but mainly very badly distributed being concentrated in the big cities. If we compare for example, the number of doctors per inhabitant in districts like Lisbon, Oporto and Coimbra we find respectively 1/367; 1/630 and 1/402, a great discrepancy with other districts, such as Viana do Castelo were we find 1/3.200 inhabitants.

Specialists are concentrated in the big cities mainly Lisbon and Oporto assistance is lacking in small cities or villages.

With all these problems of medical assistance it is obvious that protection during pregnancy and childhood is precarious. The percentage of deliveries at home without assistance is high, the infantile mortality rate is also righ and assistance to the normal child as well as the handicapped child is deficient.

To emphazise these facts we refer some statistical data (Table I).

Infantile mortality in Portugal (1st year of life), according to the classification of the World Health Organization reached the fair level only in 1970 and the good level in 1974.

This mortality rate is related to the socio-economical level of the population. The neonatal mortality which in all countries suffers a slower progress since it results mainly from a better quality of medical assistance during pregnancy, delivery and neonatal period in our country also shows a slower evolution without improvement since 1973.

Deliveries at home without assistance in 1975 - 14,91%. However if we compare this rate in Lisbon - 2,21% with a city in the north of the country Vila Real - 58,82%, we can prove the discrepancy of medical assistance in the country according to different areas.

In the field of assistance for handicapped children, several disconnected initiatives exist,without a national plan which are the cause of greater expense due to superimposed programs and difficulty in getting enough technical staff,also lack of support for the parents which leads them to look for assistance simultaneously in several places.

III - MATERIAL AND METHODS

As we try to integrate the handicapped children assisted in our Centre, we have to take into consideration the conditions of the country as they stand at the moment whith working and hoping for a change in these adverse conditions.

If, in one way special centres help the handicapped child to fully devel his potentialities, they are also means of segregation. The handicapped child, closed in an Institution during childhood and adolescence, away from his family, friends and environment, and in contact only with other handicapped children, will be totaly desintegrated from society and will have great difficulty in readapting himself to his environment, when a the end of adolescence as an adult he is considered to be "rehabilitate

Special Centres with privileged building and functional conditions, out of keeping with the real family way of life, contribute to the segregation.

Dr. Milani Comparetti in Florence has closed special Centres and has sai "we are perpetuating handicaps in our special schools and medical therap Units".

In our country we have very few special Centres and so, we do not yet have this problem which in a way is an advantage.

In our Rehabilitation Pediatric Unit we try from the day of admission t prepare the integration of the child after discharge. The parents often come to the Centre staying a few days, whenever possible, in order to learn how to deal with the child and how to continue his rehabilitation programme at home. The child, also, whenever possible goes home for weekends and holidays. We also get in touch with the local community, t know the available resources and to prepare the integration. This is no an easy task as we receive children from all parts of the country, sometimes from very inacessible areas, with very precarious conditions for integration.

In our study we have considered 80 cases consisting of all the new admissions in 1977 and the remaining cases being from 1976.

The distribution according to diagnosis (Table II) shows a higher perce tage of Cerebral Palsy, followed by Spina Bifida and Spinal Cord Injury

In Table III the distribution of cases according to age is refered. We have a lower percentage of children below 6 years because we refrain whenever possible, from admitting children mainly below 3 years, following them until this age as out-patients or in periodic follow-up clinic according to the area where they live. The children living far from the Centre, unable to come as out-patients are repported at 3-4 months inte vals, staying one week for parent guidance in a home programme.

We consider as very important that ,from the early stages the family get used to managing the child with his handicap themselves.

If the family feels that other people are going to take care of their child, they think that he is not their responsability and give up. The same happens with the community. People in a community where there are children in Special Centres, knowing nothing about them, consider tha the problem is not theirs and never get used to them.

In our Rehabilitation Unit, the children are organized in groups accordi to their stage of development and educational status. Babies and Kindergarten in one group; Primary School age divided into two sub-groups and an occupational group which includes children between 11-15 years who have already finished primary school and also children not suitable for school or kindergarten due to associated marked mental retardation.

Since we are unable to provide secondary studies in the Centre, during this year we have tried out experience of integrating 3 youngsters in the secondary school near the Centre as a transitional state for integration in their local community school after discharge and therefore only during the period that they have to be in the Centre for treatment.

We are now trying a more interdisciplinary approach in each group in order to avoid artificial conditions, integrating treatment as much as possible with in normal daily living, school and recreational activities. Going out with the child, often gives the physiotherapist a far better indication of the real needs of the particular child, then many sessions in the Physiotherapy Department.

One of our great difficulties for integration are the housing conditions of the majority of our families. Everything seems easy in the Centre, where there are no arquitectural barriers, spaces are large, the bathrooms are adapted to the handicapped, and so, the family and child can easily feel that this is what is required for him and that all is very hard and inadequate at home.

As seen in Table IV in 52,5% of our cases the housing conditions are poor which means, lack of one, two or three main basic needs — either electricity, water or bathroom, many of them with arquitectural barriers and very little living space for the whole family, generaly a big family, in one or two rooms. 23,75% of our cases have fair housing conditions, by this we mean, having the three main basic needs but still inadequate space and arquitectural barriers. The remaining 23,75% have good housing conditions with minimal arquitectural barriers and fairly good space.

The socio-economical status is also important for integration although sometimes this is not the rule, because families with lower socio-economical situation, already being used to a difficult situation accept the problem better because they are adapted to having much larger problems.

However, a handicapped child is always an emotional and physical stress and frequently requires much more equipment and aids which represent an economical inbalance.

As seen in Table IV only 10% of our cases have good socio-economical conditions.

Social security in our country is still very inadequate and children have to wait a long time for braces and wheelchairs if the families are unable to support the expense. The time they have to wait for the equipment frequently increases the time of hospitalization.

At the educational level of our families we find an even more marked deficiency. Only one case (1,25%) with good educational background.

This proves that, some families, although already having a good socio-economical situation have very little access to culture. Sometimes, living in small villages where there are no newspapers and no cultural activities, creates very few interests for them and even with some education, they are very much deprived and have almost forgotten what they have learned in school, if they ever went to it.

Table V shows the distribution of children according to the district where they live. We have children from all over the country although more from Lisbon district and other close districts which should be in the area belonging to our Centre.

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This is explained by the lack of facilities for pediatric rehabilitation throughout the country.

In some areas we even have difficulty to get a doctor able to follow-up our cases as there is only an old fashioned general practioner having no post-graduate training and so, knowing nothing about a handicapped child and the inherent problems.

This distribution of cases around the whole country makes it very difficult to visit the home and community which we feel is very important.

In order to achieve the aim of early integration in the community we try to avoid long hospitalization and if possible to avoid it altogether.

If the child lives around the area of our Centre he is followed as an out-patient. We have very good examples of successful integration of this type even in difficult cases such as a child with Cerebral Palsy - Spastic double hemiparesis and athetosis having severe speech impairment and important motor handicap. She has been followed as an out-patient and still receives speech therapy but has been attending the school of her community in the vicinity of the Centre.

This integration is always prepared in team work on a long term basis, working both with parents and teacher. The sucess of this integration depends very much upon the parent's drive and the teacher's response.

The division of special education provides itinerant teachers who support the integration in ordinary school prepare and motivate the teacher to accept the handicapped child and give individual help ,if necessary.

However, the number of these itinerant teachers is very restricted and does not cover all districts and so, this type of support is markedly insufficient.

We are encouraging the Division of Special Education to implement this project which we feel is essential to help integration and we work in very close contact with them.

For children admitted as in-patients the time of admission is frequently increased due to difficulties in getting braces, wheelchairs or others appliances due to economical problems and also sometimes delay in surgery. Social conditions at home an lack of facilities in the community have also been responsible for delay in discharge.

The average time of admission was 5-6 months with a maximum of 14 months (1 case) and a minimum of 1 month (2 cases). However we didn't count 16 cases which are still in the Centre some of them with longer periods due to complicated social problems. Taking into account these cases, the average time of admission should be increased.

In Table VI we present results regarding the integration of the 80 cases studied.

We have excluded eight cases (10%) - Five of these (6.25%) because they are still being studied and we have not reached a final conclusion about their situations and 3 (3,75%) because two of them are from African countries and we could not know the home situation and one case because he emigrated to Canada with the mother, the father being already there.

In 38,75% of our cases we can consider there is a good result regarding integration.

By this we mean: good acceptance by the family, attendance of normal school in the community and good or fair housing conditions.

So, in several cases we where able to get the family and community involved in changing some housing and school barriers.

The cases considered as fair integration (23,75%) are mainly those with poor housing conditions and many due to lack of facilities in the community mainly lack of kindergarten, so the child is not getting the necessary stimulation and social contact with other children, very important for all children, but particularly in the case of a handicapped child.

In one case there was no school in the community. This is a Spina Bifida child with limitations regarding walking, living in a village without public transport. We were unable to get transport to take him to school everyday which would be the desirable solution, but we were able to send the teacher to the home.

Another case had to go to a special school staying in a hostal for handicapped children, although he could be in normal school, because of very difficult housing conditions with arquitectural barriers. We are still following this case trying to get better housing conditions and integration in a normal school.

Other cases, due to associated motor and mental handicap went to special day school. In this group only in one case was there family rejection.

The 22 cases (27,5%) considered as poor results regarding integration were due generally to combined disadvantage situations: — housing, family acceptance and poor resources of the community. In two cases the degree and type of handicap with progressive clinical situation was also the reason. We describe in detail some of the main problems of the remaining 20 cases.

For six cases, children with associated marked mental deficiency all needing special day Centre which did not exist in the community.

In eight cases the school was very far from home or the child was rejected by either the teacher or family. All of them had very poor socio-economical and housing conditions and there was no possibility of getting social local services interested in helping the situation. There was also no itinerant teacher in the area.

Two cases, adolescent Spina Bifida girls were rejected by the family. One was admitted to a hostal for adult handicapped and the other although she went back home had to attend a school in an orthopaedic hospital without any social contact and stimulation from a normal school environment. Another case, also rejected by the family and also a Spina Bifida girl is still in the Centre. The conditions of family living are very poor and there is no school in the community. The child is going to a special school and we are trying to get a foster family which has been difficult, because of her being handicapped.

Finally three cases need professional training and since there are very few facilities for this in our country, they went home, are on a waiting list, it being very difficult for them to get a job.

Integration did not seem to us to be related to diagnosis although it seems easier in all cases of amputation and arthrogriposis. There we did not have any bad result.

The cases of cerebral palsy or other neurological conditions with associated mental handicap are more difficult to integrate.

The spina bifida cases or spinal cord lesions raise great problems in school because of incontinence when bladder training or appliances are not adequate, this being an important social barrier towards integration.

With all the problems presented, the integration of our handicapped children in family and community in our country is not an easy task.

However, evaluating the results we are encouraged to continue, expecting that sucessfull integration might be the seed for future facilities to achieve this aim.

We are in a way conservative trying to avoid forced integration which is sometimes artificial and can compromise the acceptance of the handicapped in the community.

IV - CONCLUSIONS

From our study we can conclude that the main difficulties regarding the integration of our handicapped children in the community [illegible]:

1) Precarious housing conditions and low socio-e[illegible]c income of our families, with great difficulties in the [illegible]agement of their handicapped child.
2) Inadequacy of normal schools and lack of kindergarten in the area where the child lives.
3) Lack of workshops for youngsters who, due to poor educational background, need professional training and vocational guidance instead of continuing school.
4) Lack of special schools for children with multiple handicaps.
5) Lack of specialized medical and therapeutical assistance near the area where the child lives.
6) Lack of eficiency in the social security system.
7) Adverse conditions of society in accepting the handicapped.

So, taking into consideration the final conclusions of our study, our experience of many years working with handicapped children, the conditions of our country and the solutions adopted in different countries, we propose solutions towards preserving at all costs the integration of the handicapped child in the family environment, improving the adverse conditions existing for all children, including the handicapped and with special attention to these.

We should avoid large and sophisticated Centres with privileged conditions for handicapped children and instead promote a descentralized program with several small rehabilitation centres for early diagnosis and evaluation of developmental problems in infancy and early treatment with family guidance and support.

We also stress the need to make the community responsable and aware of the problems of the handicapped in order to make their integration possible.

True integration will only be possible when there is a change in society and integration of the handicapped will be the main step towards it.

SURFACE - 92082 square Kms

INHABITANTS - 9.448.000
(demografic statistics 1975)

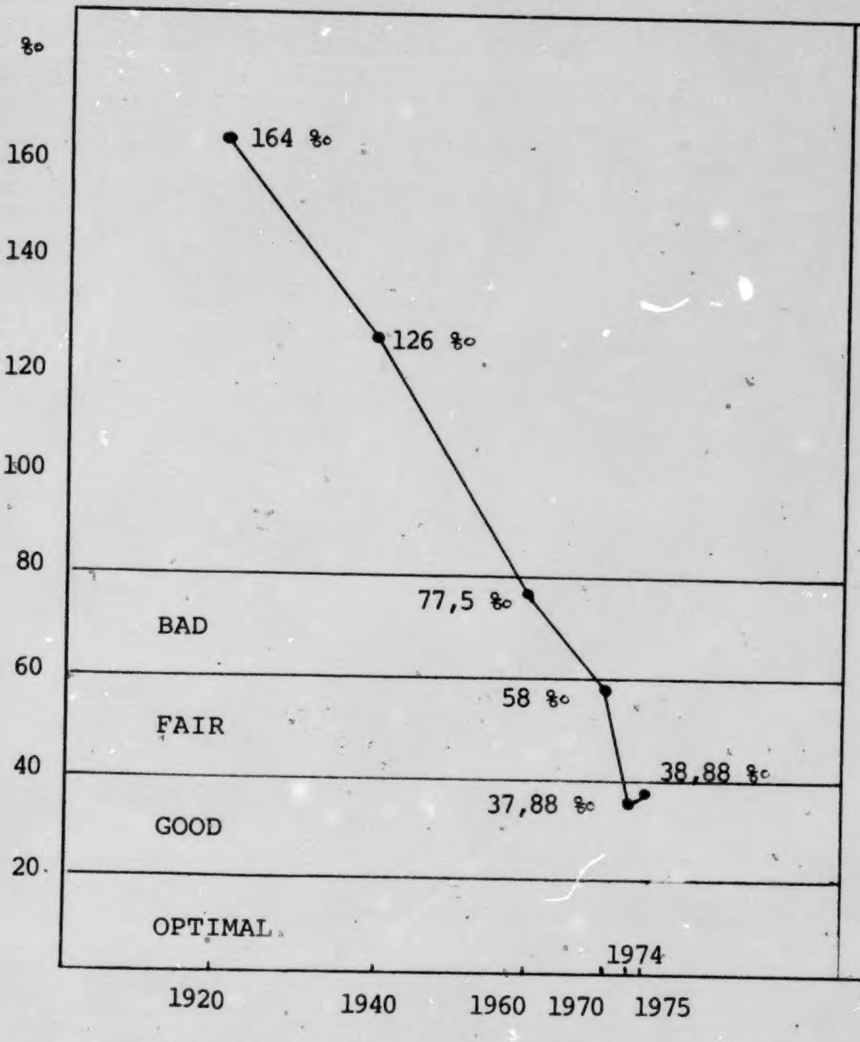
NATIONAL PER CAPITA INCOME
1970 - $684
1973 - $1261

ILLITERACY - (census 1970)
Unable to read - 33 %
University studies - 0,5 %

DOCTORS - (1975) - 1/851 Inhab.
(Sweden 1975 - 1/533 Inhab.)
Lisbon - 1/367 Inhab.
Coimbra - 1/402 "
Oporto - 1/630 "
Aveiro - 1/1.770 "
V. do Castelo - 1/3.200 Inhab.

NEONATAL MORTALITY

1952 - 28,8 ‰
1960 - 25,3 ‰
1969 - 25,4 ‰
1970 - 25,4 ‰
1972 - 19,73 ‰
1973 - 21,16 ‰
1974 - 20,93 ‰
1975 - 22,05 ‰



INFANTILE MORTALITY
(1^{st} year of life)

Classification of the W.H.O.

Optimal - < 20 ‰
Good - 20-40 ‰
Fair - 40-60 ‰
Bad - > 60 ‰

DELIVERIES WITHOUT ASSISTANCE AT HOME (1975) - 14,91 %
Lisbon - 2,21 %
Vila Real - 58,82 %

TABLE II

DIAGNOSIS	Nº of Cases	%
Cerebral Palsy	18	22,5 %
Spina Bifida	13	16,25 %
Spinal Cord Injury	13	16,25 %
Craneal Injury	7	8,75 %
Poliomyelitis	6	7,5 %
Arthrogryposis Congenita	6	7,5 %
Congenital limb deficiencies	6	7,5 %
Traumatic Amputations	5	6,25 %
Myopaties	3	3,75 %
Hemophilia	2	2,5 %
Hydrochephalus	1	1,25 %
TOTAL	80	100 %

TABLE III

AGE	Nº of Cases	%
o - 6 Years	20	25 %
7 - 10 Years	28	35 %
11 - 15 Years	32	40 %

TABLE IV

SOCIAL PROBLEMS	HOUSING CONDITIONS	SOCIO ECONOMICAL STATUS	EDUCATIONAL FAMILY LEVEL
Good	19 cases (23,75 %)	8 cases (10 %)	1 case (1,25 %)
Fair	19 cases (23,75 %)	36 cases (45 %)	25 cases (31,25 %)
Poor	42 cases (52,5 %)	36 cases (45 %)	54 cases (67,5 %)

TABLE V

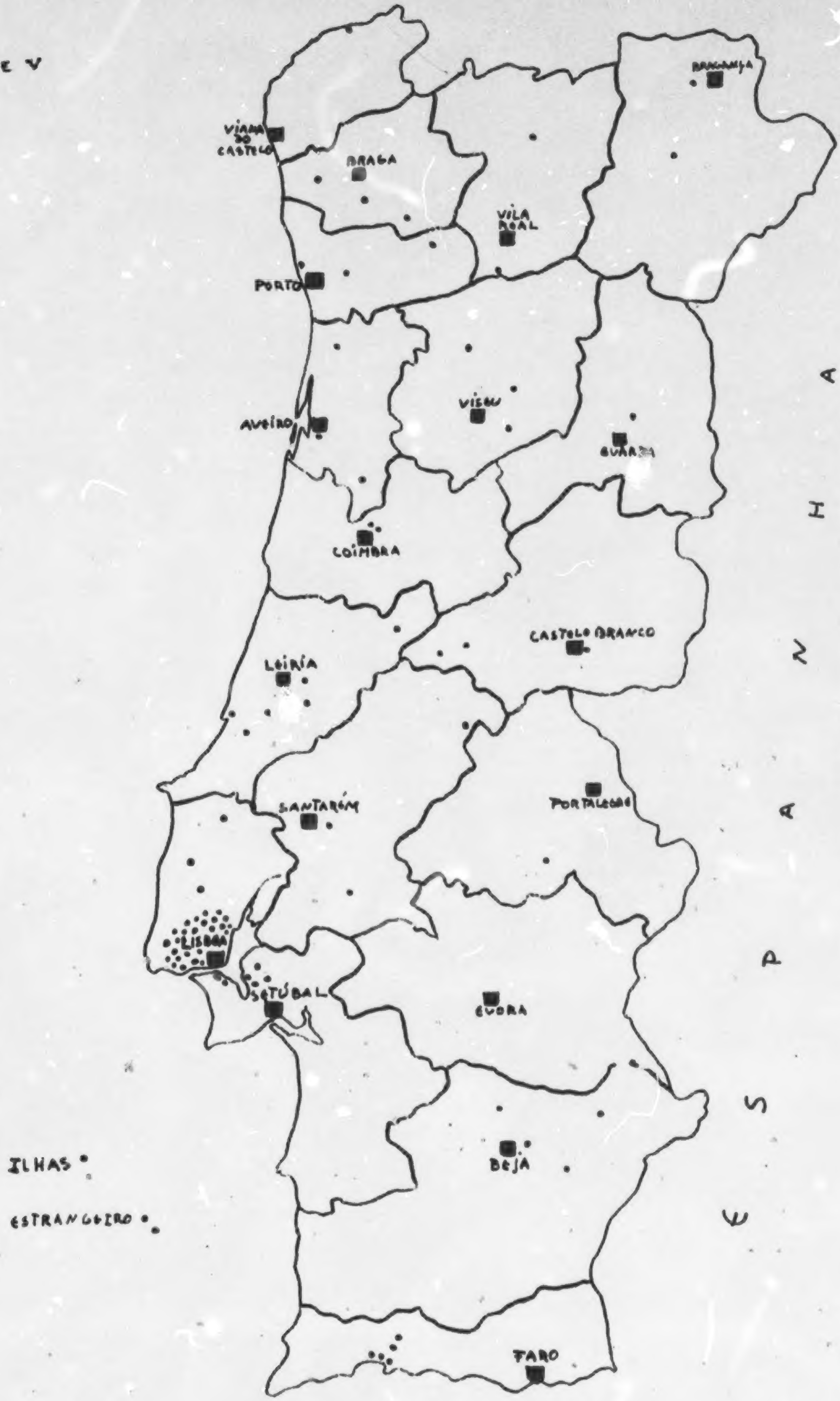

VIANA DO CASTELO
BRAGA
BRAGANÇA
VILA REAL
PORTO
AVEIRO
VISEU
GUARDA
COIMBRA
CASTELO BRANCO
LEIRIA
SANTARÉM
PORTALEGRE
LISBOA
SETÚBAL
EVORA
BEJA
FARO
ESPANHA
ILHAS •
ESTRANGEIRO •

TABLE VI

RESULTS OF INTEGRATION	Nº OF CASES	%
Good	31 cases	38,75 %
Fair	19 "	23,75 %
Poor	22 "	27,5 %
In study	5 "	6,25 %
Impossible to determine	3 "	3,75 %

Seminar 5

MENTAL HANDICAP
Chairman: *Miss M. R. Morgan*

Day to Day Living with a Handicapped Child
Gloria Calthorpe

Training Parents as Behaviour Modifiers for Severely Retarded Children
Shlomo Katz

MENTAL HANDICAP
Chairman: *Ole Petter Lossius*

Social Work Support for the Families of Mentally Handicapped Children and Adults
Miss Jo Campling

Counseling Services for Parents of Mentally Retarded Children
Ruben Reyes

THERAPY
Chairman: *Dr. E. Helander*

Travail Social avec des Groupes de Malades Atteints de Sclerose en Plaques et leur Entourage
Christiane Besson, Rose-Marie Huguet, Anne Spuhler

The Summer Family Conference—An Experience in Counseling Families of the Handicapped
Mr. Leslie D. Park

TRAINING PARENTS AS BEHAVIOR MODIFIERS FOR THEIR SEVERELY RETARDED CHILDREN

Shlomo Kats

ABSTRACT

The efficacy of using parents as behavior modifiers for working with their severely retarded children in the home is receiving more and more attention over the last few years. It has been recognised that parents provided with the appropriate knowledge and skills can be effective therapeutic agents with their children in the home and thus improve family life. Two areas of behavior which appear to be particularly relevant to the severely retarded are self-help skills and undesirable behavior in the home. As a result, these two areas have received special attention, and training programs for parents in the use of behavior modification methods have been developed. The results of the training programs, as measured by improvement in the behavior of the children, have been most promising.

INTRODUCTION

The purpose of this paper is to review and discuss the efficacy of behavior modification techniques developed for working with the severely retarded, using their parents as the therapeutic agents. Behavior modification techniques have proven to be a highly effective method for the teaching and training of severely retarded children, and especially in using nonprofessionals, parents, teachers, and nursing aides as the behavior modifiers (1,4).

The reasons for this are: Firstly, one of the salient features of this treatment technique is that methods of changing behavior can be taught fairly easily to non-professionals, because it has a set of basic principles which are capable of being grasped by the majority of persons. The approach stresses and deals with behavior which can be specified, taught and measured with relative ease and reliability (2,4). Secondly, it has been demonstrated that parents are capable and often obtain better results than professionals in cases where they are the significant others. Parents, by virtue of their natural role in the child's environment, have an emotional significance for the child which a professional person could hope to duplicate only after months or years of intensive effort. Thirdly, leaving aside the question of emotional significance and merely considering the amount of time the children spend with their parents in comparison to the professional therapist, it will be seen that given appropriate skills these figures loom large as potential influencers (4). Behavior modification techniques have been used with a variety of children having different behavior problems (3). However, this paper will confine itself to two areas, self-help skills and undesirable behavior, with severely retarded children.

TEACHING SELF HELP SKILLS

One of the areas considered as problematic for parents is the prolonged period of dependency related to retardation. Behavior modification

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techniques provide the parents with the basic theoretical knowledge and appropriate skills in helping their retarded children progress and obtain a maximal level of self-help skills within the confines of the handicap and thus reducing dependency. It provides us with a teaching method that is suitable for children with little or no language skills and very limited behavioral repertoires or experiences. Such a method is the shaping technique. The shaping technique is made up of two procedures, successive approximation and chaining. In successive approximation the behavior to be learnt is broken down into successive steps and the child is taught each step, until the total behavior is acquired. An important aspect of this procedure which differs from the conventional methods is that the child is taught in a backward fashion, one small step at a time. For example in teaching the child to take off pants, using the last step first, the child is first taught to remove his pants from only one ankle and is reinforced when the pants fall from his left foot. Then he is taught to push the pants down from his calves, take them off the right foot, then the left foot, and his is reinforced. Next the child is taught to push the pants down from his mid thighs down to his ankles, remove the pants from his right foot, then his left foot, and his is reinforced. He is then taught to take his pants down from his crotch, push them down to his ankles, remove the pants from his right foot, then his left foot, and he is reinforced. Moving from one step to the next in training proceeds at the child's own pace, and progression to the next step is dependent on the child mastering the previous step. The size of the training steps will depend upon the child. Children who learn slowly or with difficulty require smaller or more steps than those who learn faster.

Chaining refers to the connecting up of the behaviors learnt into a smooth sequence. The individual behaviors of putting on a shirt, pants, shoes, etc. are then taught in a correct sequence leading up to the child dressing himself entirely alone, using the backward procedure.

The principles of the two procedures described above can be taught with relative ease to parents. In addition, books describing how to use the methods are available (1,6). A suggested program for parents would be as follows: A short 20 hour training program is carried out with a group of up to 12 parents. During this short training period the principles and the techniques are demonstrated, preferably with the use of audio visual material, slides or video tape. Once the parents have completed the course and begin working with their children it is advisable to provide them with on going supervision and guidance for a period of a few months. Initially the supervision can be more intense, gradually reducing it as the parents become more proficient in the use of the method. This supervision helps to provide the parents with confidence and monitors their work so as to ensure maximum benefit.

Experience has demonstrated that once the parents begin to use the methods, self help skills are acquired fairly rapidly. Simple behaviors like eating and drinking can be taught within a few days and more complicated behaviors within a few weeks. Furthermore there are interesting side effects of the successful use of the method. Parents have reported increased feelings of competence, feelings of hope, satisfaction and improved attitudes towards their retarded children. After the initial training period which usually takes place outside of the home, the behavior modification and supervision are carried out in the home, in the child's natural environment and within the confines of the family's daily routine. There is no need for frequent visits to clinics and the focus is on the parent and the child within the home.

ELIMINATION OF UNDESIRABLE BEHAVIOR

Unadaptive and destructive behavior in the home is one of the most common problems that brings parents with their children for guidance and treatment. The problems are often not severe enough for hospitalization, but the parents of the child become estranged and miserable and the functioning of the home is disrupted. The purpose of the following methods is to help the parents to deal effectively with these destructive or undesirable behaviors within the home environment.

These undesirable behaviors, which create considerable management problems and are described in professional literature, are dangerous self mutilation, violent and unpredictable temper outbursts, physical attacks on peers, chronic high rate repetitive movements, disruptive screaming and crying and destruction of windows, clothing and other household goods. The emphasis here is on reducing or eliminating and inappropriate behaviors and a review of the literature (2) indicates that one technique which appears to achieve the best results with these behaviors are aversive techniques: punishment.

The use of punishment understandably generates a great deal of emotion, misunderstanding and opposition. When reviewing the use of punishment one has to keep a number of issues in mind. In most cases the maladjustive behavior of the severely retarded child in the home is disruptive and demoralizing. It often prevents the acquisition of more desirable behavior and any attempt to teach more adaptive and constructive behavior is thwarted by the inappropriate behavior. Often the behavior presents a real threat to the child himself and if not removed, could in the long run result in death. To prevent this we sometimes find that a retarded child is kept tied down to the bed because he threatens his life by his head banging behavior. This is a method of control. However, by applying a mild electric shock, less painful than a doctor's needle every time the child bangs his head, we can remove this behavior in a short period. What is the moral thing to do - to use the shock to remove the unadaptive behavior which is restricting and endangering the child's life, or to condone the destructive behavior? I think mothers have little trouble making such a choice. Furthermore, in their dealing with aggressive or self destructive behavior, it would not be surprising if parents resorted to punishment out of frustration and despair. It would appear that it is more desirable to teach parents effective and controlled use of punishment to eliminate these behaviors.

Punishment procedures that have been used with the retarded can be described on the basis of the operations followed. These would include (a) electric shock, (b) physical restraint, strapping to the chair, (c) various procedures of time out from positive reinforcement, for example placement in an isolation room following inappropriate behavior.

The use of shock is recommended and found to be effective with single specific behaviors which occured with little variation in frequency or type and which seldom involved direct interaction with others, for example head banging, biting oneself (3). Duker (2) suggests two additional criteria for deciding if and when to use shock. Firstly if the aversive sensation produced by the electrical stimulation exceeds or is equal to the aversive sensation the person administers to himself by performing his undesired behaviors, then one should reconsider the use of shock. Secondly, it should be applied only after a functional analysis of the problem behavior has been carried out. This allows one to identify the stimulus control and the maintaining contingencies of reinforcement and on the basis of this analysis, it can be deduced that other methods would be less effective.

The most common shock method used is by a hand held inductorium contingent upon inappropriate behavior. Another method is where electrodes are placed on parts of the body and the shock is remotely controlled by a hand held transmitter. Physical restraint ranges in form and severity. In one case the inappropriate behavior resulted in the subject's arm being held down onto his lap and secondary aversive cues of verbal disapproval are developed by pairing these cues with movement restraint. Another technique is the use of restraining jackets, not to restrict behavior but rather as aversive consequences to suppress its occurence. On occurence of the target behavior the subject is immediately restrained to a bed or chair for various periods of time. A third method is time out procedures where the subject is removed to a time out area when the target behavior appears. Time out procedures involve the removal of all social reinforcers for a period of time, thus time out from positive reinforcement, by social isolation from social interactions. Studies using the various punishment techniques have described differing degrees of success, but the majority of the studies seem to indicate the general efficacy of the techniques (2,3,5). Here too as in the teaching of self help skills, the training of parents is a fairly simple procedure.

The purpose of this paper was to briefly review two areas where parents could be trained in the use of behavior modification. These techniques can also be successfully used in teaching social behavior and cognitive skills. Parents by their natural role as care givers can become more effective in their roles through the use of these techniques. All the basic principles involved in the treatment process are explicit, they can be fairly easily communicated, they can be applied under direction by persons not having very much formal education and the focus upon behavior allows rather accurate monitoring and evaluation. The most common report heard from parents who participated in the training program is that the training program helps them to become more positive and efficient in interacting with their retarded child.

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SOCIAL WORK SUPPORT FOR THE FAMILIES OF MENTALLY HANDICAPPED CHILDREN AND ADULTS.

*Jo Campling

Abstract

Introduction. Discussion of present situation. Needs and expectations of the families. Results of survey on the social work support role for the families of mentally handicapped persons carried out on approximately 100 social workers in local authority social service departments and voluntary organisations. Examples of good practice. Recommendations, including implications for training.

Text

The current move towards community care, in addition to the statutory obligations placed on local authority social service departments by the Chronically Sick and Disabled Persons' Act 1970 and the influence of documents like Better Services for the Mentally Handicapped, 1971 have had considerable implications on social work with the handicapped. Nowhere is this more obvious than in the field of mental handicap, where more emphasis is now placed on providing care and support services for this group and their families in their own homes rather than in the hospitals. The Court Report in 1977 said 'There is no medical or nursing reason why half the children at present in long-stay care in mental subnormality hospitals should have been admitted in the first place. Their major need was for a home'. Yet Better Services acknowledged the stress that a severely handicapped child or adult can cause in a family. At the same time the report estimated that 80% of all mentally handicapped children and 40% adults lived at home with their families with little outside support. If community care is not just to become family care for this group, then a variety of local services has to be provided so that the mentally handicapped person and his family can lead as happy and as full a life as possible. One of the most important of these services is that provided by the social worker in support of the family with a mentally handicapped child or adult. To date this service has been scarcely examined or indeed, delivered. As early as 1957 the Royal Commission talked about 'more social support for the mentally handicapped and their families' and 'the lack of other services which might make it possible for their own families to care for the mentally handicapped'.

The needs and expectations of families in terms of social work support have already been well documented. The Sheffield Development Project summed these up as, '... help with problems of adjustment, emotional relationship difficulties and practical support ... making available to the family the whole range of social services both statutory and voluntary'. The families themselves tend to emphasise the need for 'practical help rather than good advice', as one parent said. Michael Bayley in his excellent study of families caring for the mentally handicapped at home, has stressed the routine sequence of events which

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are involved in such care, which he describes as the 'daily grind'. He goes on to describe a mother's irritation with a young social worker who wanted to explore feelings but who had no experience of bringing up children and no practical help to offer. On the other hand all the research has highlighted parental isolation and the need for emotional support, particularly at the crisis points. Edna Wallace has shown how parents want someone to interpret what the medical profession say, (a point also made in the King's Fund Study) to help them come to terms with feelings of isolation and grief and to assist them to plan for the future. In other words there needs to be a continual commitment to a family to enable parents to keep a mentally handicapped child or adult at home.

The 1971 White Paper says that 'the person best placed to act as co-ordinator [of services] is likely to be the social worker'. And indeed the role of the social worker is crucial as a member of the support team of the family. However, the mentally handicapped are notoriously low on the list of priorities of social service departments, partly due to the shortage of social workers and partly due to the lack of training, so that actual practice has fallen far short of expectation. Teaching on courses about mental handicap, particularly the needs of families, is minimal, even non-existent. Whilst we know a great deal about family expectations, we have little information about how social workers perceive their support role and how they actually carry it out. This is what I wanted to discover in my study.

Over 100 questionnaires were sent out to social workers in local authorities and voluntary organisations. Seventy-two completed forms were returned, fifty of whom had families with mentally handicapped children and adults on their caseloads. The number of families on each worker's caseload ranged from one to thirty-two and fifty-seven (the latter were specialist social workers) and the average number per worker was eight. Most social workers were unable to be specific about the frequency of their visits because these varied according to the changes in family circumstances but the average was once every two months. This group of workers were asked to define their roles and estimate what they were able to achieve. The major theme to emerge from their replies was the joint importance given to providing skilled emotional support and practical help, including co-ordinating other care and supportive services. All respondents (whether they had families with mentally handicapped on their caseloads or not) were asked to describe the ideal social work role with such families. Their replies followed the same pattern.

One specialist worker summed it up in this way, 'To enable the parents to come to terms with the handicap and help them reach as normal a life as possible, i.e. providing emotional support at the crisis time of diagnosis and throughout the child's early years and also providing as much practical help as is available in order to make the child's management as stress-free as possible. Also making sure that the community services are aware of the families' existence and establishing self-help groups or just putting one family in touch with another if applicable'. Rarely was one aspect of the support role stressed at the expense of another. An exception was the case of a young Mauritian couple with a mongol baby whose main problem was the cultural taboos attached to handicap. The social work emphasis here was in helping the parents to overcome the guilt they felt in having produced a handicapped child. The same social worker referred to her attempts to provide practical assistance as the 'easy' way of showing help when faced with the difficult task of providing skilled emotional support which might not produce obvious movement and progress.

A number of social workers stressed the need for self-help groups and their role in helping to establish these. Some went further and talked of involving the community in a supportive way towards the families. A minority talked about political action with parents in pressure groups to press for better resources. An awareness of the needs of the whole family was much in evidence. Schaffer has described the 'too cohesive family' where not only the mother's life but also the father's and the siblings become excessively centred on the handicapped person, to the detriment of the emotional growth and functioning of the family unit which becomes dominated by the burden of care. One worker expressed it thus, 'I aim to help the parents to come to terms with the fact of handicap and to cope in such a way that the rest of the family's life is not distorted'. Another said, 'I help the parents to get an overall view of their responsibilities to all their children, not just the handicapped'. Essentially all the sample saw their role as one of emotional support and practical assistance, involving close liaison with other agencies. Services for this group are so fragmented that parents may fall in and out of contact with a number of different agencies, so that a 'direction indicator', as the King's Fund Study puts it, is required.

On the whole social workers were very realistic about their achievements, identifying lack of resources, time, knowledge and training as the barriers to fulfilling their tasks in the way they would like. 'Given present resources and current cutbacks, achievements are limited'. Another referred to her 'fight for time' which was not available because of pressing statutory duties. In this respect the specialist fares much better and this was often pointed out by the generic worker. A fundamental aspect of work with these families is its time-consuming, long-term nature. In one of the most successful cases described, the social worker had been involved with the family for eight years, and had built-up a considerable specialist knowledge in addition to a close and trusting relationship with the family, which involved a partnership in planning to 1982. Such a consistent, long-term involvement by one social worker must be very rare in overstretched local authority social service departments. Too often the work is containment of family problems at crisis points. As one social worker said, 'Work with the mentally handciapped is given low priority by local authorities. To do it effectively one needs to give a lot of time to it - another example of how Seebohm has meant that some groups of clients have lost out'. Social workers with heavy caseloads have to use the majority of their time in dealing with crisis and statutory duties rather than providing support to families who do not appear to have immediate pressing needs. Newly referred families may find their practical requests dealt with but because of pressure of time and resources, then do not become part of a long-term caseload unless their need for personal support is obvious or family breakdown is threatened.

Lack of sufficient expertise was also recognised. A pre-Seebohm mental health officer said, 'I am very conscious of my fragmented approach now. I don't have a wide knowledge of resources and trends in the borough or

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region. There is no central information resource to call upon. I don't have (as I had) a good working relationship with a consultant in a subnormality hospital for assessment etc.'. The need for a specialised service was often mentioned, and the implications for training were not overlooked. For example, 'Social workers are leaving training courses without much knowledge of mental handicap and do not see this as an option for specialisation, backed by in-service training. We need to inject a new focus into training so that there is a demand for this specific area of post-qualifying study if we are to offer families the support they deserve'.

Evidence of good practice does exist and agencies are engaged in experiments to provide better support for the families of mentally handicapped children and adults, for example the FISH scheme in the London Borough of Haringey or the action research project at the University of York. The latter involves 'resource workers', all qualified and with previous experience of mental handicap. Their role is to bring all kinds of statutory and voluntary, formal and informal resources into the families of mentally handicapped children. The resource worker acts as an easily identifiable person who can deal with any problem, including referrals to other specialists; who can co-ordinate and improve the delivery of services to the family; who can supply information, detect unmet needs and provide the kind of consistent and on-going support so badly needed by this group of families. This project complements research work being done elsewhere and will provide the Department of Health and Social Security with findings which should influence policy decisions in the 1980s.

Some of those policy decisions may have implications for training. The Central Council for Education and Training in Social Work (CCETSW), the British Association of Social Workers (BASW) and the National Association for Mental Health (MIND) have already put forward proposals for a specialised service. They all recognise skilled social work support as the vital factor in the services for the mentally handicapped. Without it the other community services will not be used and will not be able to develop fully. Last year a MIND Working Party recommended the establishment of a group of 1440 specialist social workers in the field of mental handicap. This would require a degree of specialised training for 170 students on CQSW courses each year over a ten year period and a crash programme of in-service and further education training. This crash programme would aim to improve the practice of many additional social workers in helping mentally handicapped people and their families, as well as assisting towards the development of a body of specialist social workers, which the Working Party considered absolutely essential. The economic benefits to be gained by giving full professional support to parents caring for mentally handicapped children and adults are obvious but most important, this support is essential if the concept of community care is to become a reality for these families.

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SUMMARY

SOCIAL WORK WITH GROUPS OF MULTIPLE SCLEROSIS (MS) PATIENTS AND THEIR SURROUNDINGS.

Christiane BESSON, Rose-Marie HUGUET and Anne SPUHLER.

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The idea of group social work (GSW) amongst MS patients and in their surroundings grew out of the practice of individualising social work since 1970 in the Pro Infirmis (Swiss institution for aid to the handicapped), Vaud department, in order to promote mutual aid and to respond to whatever needs are expressed. The problems concern the disease, dependence on others, solitude, the slowing down of life, stopping work, feelings of uselessness etc.

In these open, long-term therapy groups with socio-cultural issues, help should be mainly derived from learning to listen and exchange through warm, open relationships, from identifying and from the scope for expressing negative emotions and exploring conflicts within the group.

Since after several years' existence the GSW objectives were achieved, the MS groups (3 of MS patients and 1 of spouses) are being transformed into spare-time groups. Days of work and reflection with a large group (arising from inter-group exchanges) are going to be more important.

As for us social workers, we are thinking about the form which should be given to possible new groups of patients and their friends and relations.

SOCIAL WORK WITH GROUPS OF MULTIPLE SCLEROSIS (MS) PATIENTS AND THEIR SURROUNDINGS

Christiane BESSON, Rose-Marie HUGUET and Anne SPUHLER.

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It was from the practise itself of individual social work that the idea sprang up at Pro Infirmis of group social work (GSW) with multiple sclerosis patients. Pro Infirmis is a Swiss institution for aid to physically and mentally handicapped patients. It is private but subsidised by the Swiss Social Security organisations. Similar activities exist and are developing in other canton departments of the Pro Infirmis but here we wish to discuss an experiment which has been going on in the canton of Vaud since 1970. We thought that group work was a means of teaching mutual aid to the handicapped and their families and helping them to find their own form of aid. We have proposed and used this means to respond to needs expressed directly by these persons or heard by social workers of the department.

What are the problems?

1) Problems caused by the disease itself, progressive, fluctuating and incurable paralysis.
2) Dependence on others.
3) Difficulty in finding balance within the family.
4) Solitude, loneliness and suffering.
5) Slowing down of life.
6) Stopping work and giving up a career.
7) Feelings of no longer being useful - the feeling of existing under these conditions.

What criteria were our groups based on?

- Persons suffering from MS, knowing their diagnosis, and people living with them.
- People able to join in a group, feeling a certain desire to share their troubles with others, also their questions and square time.
- A mixed group if possible, including all ages (30 to 60 years).

- People not all at the same stage of development of their disease.
- Small groups of 7 to 10 persons.

These groups refer to the GSW theory (see work by Gisela Konopka) and tend to be more therapy groups dealing with socio-cultural issues. They are characterised by their openeness and their long-term nature.

History of the groups

The first group of MS patients started at the end of 1970 with 8 participants in the Lausanne region.

At present there are 14 but due to the irregular attendance (because of the illness) there are seldom more than 8 to 9 participants at the meetings.

During the development of the first group and the outings with the spouses which happened quite naturally, we had the idea of creating a spouse group of MS patients under the leadership of another social worker starting from May 1973.

A second group of MS patients was started at the same time, also at Lausanne, then a third started but this time outside the town; the participants come from several villages and meet in a little village in the actual centre of the canton of Vaud.

Finally in January 1977 a fourth group started in a tiny village in the North of the canton with the MS patients in the area.

Little by little the family meetings and exchanges between the groups gave birth to a large group which has opened up possibilities of doing new and original work.

The meetings of the groups, lasting about 2 hours, take place every fortnight, stopping during the holidays. For the patient groups the choice of a meeting place is dictated by the accessibility for wheelchairs. There is also the problem of transport for these groups: in certain cases we have at our disposal a Handicap-Bus which can take 4 wheelchairs.

How have we been working in the different groups?

We work on verbal and non-verbal levels. On the verbal level by discussion, sharing ideas, questions, worries of the moment which one or several members may have and their echoes amongst the others, by studying a book, a film etc.; on the non-verbal level we have used several methods, amongst others manual work, games, outings, meals; new forms of relating have been created in this way. All these verbal and non-verbal elements correspond to the needs of the members at a given moment of their life and that of the group and contribute to the "therapy". Depending on the time and the needs of the group and its members, it could be that the emphasis should preferably be put on doing things together, being together or discussing together.

What have we been talking about?

It is said: "This illness is really horrible". "At present there is no remedy". It is only because of this disease that these groups are in existence, that the members of the different groups participate and that they have the need to speak to others who experience the same difficulties in their bodies, their spirits and their hearts. It is here that we find the objectives for starting the groups and shall summarise them in the following way:

- going out of the house, which enables the patient to see his family and illness with some perspective and breaks the loneliness;
- coping with the difficulties of the illness: acceptance, rebellion, family difficulties;
- thinking in terms of a restricted situation which is produced by the illness (lecture, films);
- taking action on social issues concerning the illness (MS campaign, architectural barriers, etc);
- enjoying oneself together with outings sometimes combined with visits to institutions, meals, walks, allowing contact with society as a whole; experencing moments of happiness together.

In the different groups, each person expresses himself in a free, spontaneous and personal manner; it is a question of relating oneself to the ill or healthy spouse; we have noticed a great similarity in the themes which occur in the different groups; those that are "ill" perhaps touch upon them more directly as they are all affected. Their illness can be seen and this allows a more rapid identification, a more direct approach and help for questions such as bodily suffering, auxiliary aids, food, organisation of daily life, holidays, temporary employment; or transport, doctors, quacks, different treatments, loss of self-esteem, inactivity, isolation due to the illness. At the beginning at any rate, the spouses found it difficult not to run away with all the talking of the illness and the sick person; there was a tendency to forget that they also existed.

In each of the groups we all make a large effort to try to be more clear about ourselves and to try and understand how the other -the ill or healthy spouse- is seeing us, is managing with us, is able to organise his or her daily life so that it becomes worthwhile. But it is not enough to talk, it is still necessary to live.....

How is help given and on what levels?

This is our big question! Do the members find help and relief through these groups? Can a slight change in attitude be initiated? How can this be verified? We have only indications and all the same....

Help should be mainly given by learning to listen, by more direct expression, by communication, by the possibility of open warm relationships, by the possibility of expressing negative feelings, of exploring conflicts within the group without too much danger, by giving special attention, by making use of absences, by identification.

We have distinguished three levels of extending help: the personal level, the marital and family level and the social level.

On the personal level the group offers the opportunity of sharing concrete or psychological problems with their fellow beings ("There is nowhere where we can talk, we are never understood") of finding ways of responding together in ways which would not necessarily arise or be understood in encounters with a social worker by himself.

On the marital-family level, we have tried to see in each group what the attitudes were towards the spouse in order to understand the other better; we have tried to keep calm during times of conflict.

On the level of social integration, it seems that help is more apparent for the sick person than for the spouse; the group has allowed MS patients who are very dependent to realise that they are capable of acting, of mobilising themselves, of taking various actions concerning taxes, sales, representations. Perhaps for those not affected by the illness, the most concrete form of help on the social level would be for them to dare to live, to show themselves, go on holiday, to the seaside, to the restaurant with a spouse or child suffering from MS, to communicate with passers-by, neighbours, etc.

Does our work have a specific character?

We do not wish to find something specific here in the individual work but rather to point out some original features which we consider to be important in these groups. The problems set by MS partly determine the life and the form of these groups as well as our role.

Right from the beginning we are brought back, together with the members of the groups, to basic problems of the meaning of existence, of suffering and of illness.

The members take trouble to consider who might benefit from such a group and so open themselves up to the outside world, make an act of mutual aid, the groups are open.

When the patients or spouses enter the group it is at different points in the progress of the illness. However, during the course of weeks and years they will have to confront new difficulties. Thus the long-term nature is also a characteristic of these groups.

It is clear that learning to be open and to accept slows down the rhythm of the group but does not prevent it from moving towards independence. In daily life the reciprocal dependence between the "sick" and the "healthy" makes it more difficult to experience this independence in the group and makes it one of our central aims just as the expression of aggression which if it makes us "rejected or rejecting" in the context causes guilt feelings.

The work with the life of the group itself passing from dependence to conflict so as to reach cohesion and independence as well as always reminding ourselves at the end of the group that the problems we are dealing with are not transitory ....

We have tried to have days of intergroup meetings with and without children. This idea came from the members themselves. We were able to take advantage of this large group, where it is more easy to hide oneself or show oneself of one's own free will. Here there is an opportunity of living out a part of what we talk about seperately in order to be able to talk about it better and to be able to manage better together. This parallel and communal life, making use of these movements towards the other, allow us to catch sight of the long-term objectives which we consider to be original in our initiative in social work with groups.

What are the present trends and the future of the different groups?

One of the specific features of these groups as we have seen above, is the long duration because of the illness.

Experiences which have been made directly in social work with the groups involving listening, self-expression, mutual help, sharing the life of the group (meeting one another, confronting one another, leaving one another) cannot be repeated with the same group. There comes a moment when we reach certain results on the individual and group level. Although the objectives associated with the social work of the group have been met, the MS patients who have been meeting for three or even five years still want to come together. But their physical dependence forms almost insurmountable barriers to such a desire for coming together. What is to be done then? Transform these GSW groups into leisure groups with an ergotherapist looking after them or volunteers who are supported. This does not mean that these persons will no longer need a specific type of social help. This is always provided on the individual level at Pro Infirmis but they have also learned to benefit from mutual aid and to ask for what they want.

The spouse group has been going for five years and for two years in its present form. We have worked by three month contracts during the past year; the cohesion of the group has been reinforced in this way as well as the support provided between the sessions without the presence of the social worker. We have arrived at the idea of openness through information on the social and psychological problems of the MS patient's milieu obtained from student nurses and through personal experience outside the group with a three-monthly support group organised for the autumn of 1978.

We have still some plans for the large group. We think that it is useful to provide a day of reflection and work once a year on a theme which directly affects the life of the MS patient and his immediate circle. Little by little we hope to encourage the patients and their spouses to prepare and organise these days, deriving support from the ground already covered in the social work with the groups.

We still have a completely new project: one of our social work colleagues has received a request from a relatively young couple to work together on the problems pertaining to the onset of the illness, stopping work and living together. We have already met three couples and are still hesitating.

These are our questions after these various experiences

- are we going to form a couples group?
- are we rather going to work with persons at the beginning of their illness both unmarried and married?
- are we going to have an open group and long-term or closed intensive, short-term and then what are we going to do with the slowing down of the life of the patients?
- are we going to continue to mix the ages or not?
- are we going to bring patients together who are at the same stage of their illness?

Such are the questions which we are asking and which we try to answer by the work itself and by reflection and by the encounters and exchange of views which such a congress can bring about.

THE SUMMER FAMILY CONFERENCE: AN EXPERIENCE IN COUNSELLING FAMILIES OF THE HANDICAPPED

LESLIE D. PARK*

ABSTRACT:

Since 1968, United Cerebral Palsy of New York City, Inc. has conducted a Summer Family Conference for members of families with young handicapped children living in the New York City area. The purpose of this conference is to provide an orientation and counselling session for families who are just beginning to face the lifelong problems of caring for a disabled child in the home.

Approximately 25 to 30 families, representing between 150 to 175 family members, attend this conference from all sections of New York City. Conducted on the campus of Monmouth College in West Long Branch, New Jersey, the conference has proven to be the most outstanding and effective counselling program developed for families of the handicapped.

A survey of all family participants completed in 1977 concluded that conference objectives had been translated into meaningful behavioral changes within the homes of the children represented. Subsequent interviews with parents have revealed that no counselling experience with physician, educator or clergymen, has been as meaningful in total understanding and orientation to the problem as this experience.

TEXT

When intensive efforts of mind, spirit or body have been undertaken, men have always thought of a special retreat or training place. Religious pilgrims have gone to the mountains for meditation, learned men have sought the company of other scholars or books, and athletes prepared themselves intensively in training camps apart from their regular routines. Why not apply this principle to the education of families of young handicapped children who are now mobilizing mind and spirit to cope with the most difficult problem many of them will face in their lifetime? This thinking led to the idea of the Summer Family Conference.

Families and children in the largest city in the United States find unrelenting circumstances battering their lives on a daily basis. Economic, racial and complex social problems are a constant backdrop to life in this metropolis. In addition, a large percentage of the population does not speak the English language and are from alien cultures. These circumstances compound the already existing problems of families with handicapped children.

United Cerebral Palsy (UCP) of New York City in more than 25 years of service has endeavored to provide a comprehensive program in 11 different centers throughout New York City. The program serves more than 1800 handicapped clients each month. How do the families of handicapped individuals link up with this agency and the essential services it provides? How can a family know what it must do in the home to provide the optimum environ-

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ment for the development of the handicapped child? Is it just mother, or do other family members have a role to play in the adjustment of a handicapped child in the home? These are but a few of the many questions which must be faced as families of young handicapped children prepare to be of maximum help to the child. Maintaining whatever normalcy a family can retain under these circumstances is difficult at best.

In 1970, a significant program was undertaken by UCP of New York City, Inc. funded through the U.S. Office of Education. This was a project to develop a demonstration "Early Education Program" for pre-school handicapped children. It was one of three such demonstration programs in the country and was designed to experiment with techniques leading to more suitable education for young handicapped children.

Early in the project the question of how the family was to be involved came up. What initial steps should be taken to provide for family orientation and subsequent involvement in the rehabilitation process? Experience had taught us that holding monthly meetings among interested parents was too limited. Often, more questions were raised than were answered and parents found that the subjects were often not appropriate to their particular circumstances.

Because so many families came from poor economic situations which included inadequate housing, the idea of a "retreat" had great appeal. Such a retreat in the country, in a setting that was conducive to learning, was especially appealing.

The setting of a college campus in a rural atmosphere seemed to offer the most ideal location for the initial parent conference. The selection of Monmouth College in West Long Branch, New Jersey, was extremely fortunate, since this campus offered available facilities for conferences of this type when regular college students were not in session. The arrangement of dormitory space where families could live as a unit, and where appropriate services could be provided for young children, was quite ideal.

It was decided that a general theme for these conferences should be "All Barriers Down". Barriers of language, dress and social strata must be eliminated as we jointly addressed ourselves to learning how to more effectively care for the handicapped in the home and the community. Informal dress was encouraged and no staff members were distinguished by clothing or appearance. Perhaps our rapport with parents would be better if we could eliminate such barriers. Our first conference in the Summer of 1970 proved this to be absolutely correct. The general atmosphere of informality developed along with a great interest in learning. Parents were at a teachable stage while their children were young and these parents wanted to know what more could be done for their children in the home, as well as in the clinics, schools, and rehabilitation centers. As staff members of our agency, we became partners and learners together in an intensive three-day experience.

FORMAT FOR LEARNING

It was decided that this conference must do everything possible to strengthen the family unit as well as provide a good educational experience. For this reason, families were encouraged to live together, husbands and wives attended lectures and discussion groups together while children freely mingled with other children in organized and supervised daytime activities, returning to their families in the late afternoon and evening.

The format for learning was well thought-out and provided practical seminars and lectures each morning. These lectures concentrated on primary subjects, such as:

> What can I expect from the medical profession in the future?
>
> What is different about learning for the brain-injured child?
>
> What things can I do in the home that would be most helpful?

From the very beginning the emphasis was on demonstration and practical "how to" activities.

In each succeeding morning a pedagogical session was led by a physician, an educator, or a team of therapists who demonstrated simple assistive devices that could be used in the home. This format proved to be very good and has generally been repeated, with some modifications, each year. We found that parents were quick to raise questions in this informal atmosphere and discussions quickly ensued among parents comparing notes on how their children behaved in various circumstances and how they were coping with individual problems.

In subsequent years a special session on the specific resources of United Cerebral Palsy was presented. This theme provided assurance that we would be here to share the burden with them so long as they lived. It was made clear that the agency was here as long they had the problem and there were no "cut-off points" when a child reached age 21 or when the financial fortunes of the families rose or fell. Many parents spoke candidly of the positive effect this had on reducing their anxiety. These morning general sessions revealed many interesting sidelights. The hostility and resentment toward organized medicine was immediately apparent. No doubt this related to "blaming the doctor" for having a cerebral palsied child. It was also apparent that parents often have unrealistic educational aspirations for their very limited children. Frank discussions of educational objectives and techniques tended to make these more realistic.

Informal group discussions were held each afternoon in sheltered areas under the trees. Parents from the same neighborhoods (called boroughs in New York City) met together in discussions led by a team of social workers and psychologists. Parents were encouraged to express their feelings about having a handicapped child and to explain their special techniques in handling the child at home. Questions about the relationship of the child to other children in the family and the neighborhood were frankly discussed.

It soon became apparent that it was in these sessions that the real feelings of the parents were most effectively voiced. Group leaders with great sensitivity and skill were able to encourage parents to openly express their feelings without any guilt or shame. It was not unusual to hear a husband or wife openly admit that they had never heard the feelings of their spouse expressed before this. Likewise, a self-teaching attitude crept in among the parent groups so that they soon were counselling one another and sharing feelings never expressed before. This highly therapeutic atmosphere has prevailed in almost every conference since the initial one.

For several years meetings were held among the brothers and sisters of the handicapped to encourage a similar type of discussion. Teenage brothers and sisters spoke about what it meant to have a handicapped brother or sister living in the home, how this affected their friendships, etc. For the most part these sessions were not entirely successful and were abandoned after a rather limited period of time.

Probably the most effective part of the conference came from the informal and unscheduled discussions which were held in the afternoon and the evening among the staff members. With highly professional staff serving as conference faculty, parents were able to openly discuss any issue relating to care in an informal and relaxed atmosphere. It was encouraging to see how easily parents spoke of their problems when they were at the swimming pool or the beach. Questions came up which would never have been posed in the formidable environment of the doctor's office.

CHILDREN'S SCHEDULE

Children attending the conference were grouped according to age and involved in a day-camp type experience. With competent group leaders these children enjoyed a variety of recreational activities and were treated to interesting outdoor summer experience. City youngsters enjoyed exploring the wonders of the country and many developed new friendships which have persisted over the years.

We soon realized that in the recreation program for the children we were really introducing many of them to middle-class American standards. Many Puerto Rican and Black children from the poverty areas of the city were exposed to the way college students lived on a college campus. One young Black boy was heard to say as he entered the bus to return home, "I would like to come to this college someday."

Afternoon and evening periods during the conference were times for recreational activities and relaxation. Trips to the ocean-front (just a mile away) were provided regularly and group evening activities planned for those who wished to participate. The most popular of evening activities was the square-dance program which had wide participation by both families and children. One was quick to observe that many families with young handicapped children had simply not learned to play. Family groups included grandmothers and other adults living in the household. It was a revealing experience to see parents and other adults enjoying group activities of this kind for the first time in many years.

Baby-sitters were provided for parents with young children in the evenings so that they might have some opportunity to be off by themselves if they wished. The nearby ocean-front boardwalks and recreation opportunities provided some an incentive to get away from the college campus for brief periods of time.

The unqualified success of this conference program is best seen in the responses from those who answered questionnaires relating to their experience over the past eight years (see attached chart).

CONCLUSION

Where an organization, community, or group of parents can institute a similar type of parent activity, it is evident that the effectiveness is far-reaching and can provide the instruction and the hope that parents of young handicapped children are looking for. Followed up by meaningful program services, this type of parent conference and orientation easily becomes an effective instrument for developing meaningful relationships between agency personnel and families of the handicapped.

CHART I
PARENT CONFERENCE SURVEY

In the summer of 1977, a total of 191 questionnaires were mailed to families who had participated in the conference since 1970. The returns brought back 75 completed questionnaires, with 51 returned "address unknown". The remaining 65 did not respond, or responded too late to be tabulated.

From all completed questionnaires, the following statements received more than 50% checked "EXTREMELY HELPFUL" (as apposed to HELPFUL or NOT HELPFUL):

Feeling free to contact UCP staff.

Knowledge of other parents sharing similar problems.

Working relationship with UCP staff.

Understanding of CP as a condition.

Ability to speak to others about child's condition.

Considering future needs of child.

Using conference methods for feeding child.

Helping child's educational progress.

Encouraging child's independence.

Using conference methods for dressing child.

The full survey report and additional information on the conference is available by writing:

Executive Director
United Cerebral Palsy of New York City, Inc.
122 East 23rd Street
New York, New York 10010, U.S.A.

PREVENTION—INTEGRATION: PRIORITIES FOR THE '80s

Introduction

Mr. J. Sarney, CAE

1980 WORLD CONGRESS
"PREVENTION - INTEGRATION - PRIORITIES FOR THE 80's"

Mr. J.R. Sarney

The Canadian Rehabilitation Council for the Disabled is proud to have been selected to host the 1980 World Congress of Rehabilitation International.

In co-operation with Rehabilitation International we are planning to make it the most outstanding global conference on rehabilitation ever held anywhere...so please note the dates of June 22 to 27, 1980 - and the location of Winnipeg, Canada.

As you are already aware, the 1980 World Congress will have a product that will be identified as the Rehabilitation International *"Charter for the 80's"*. The charter will constitute a basic document on international priorities in the disability prevention and rehabilitation fields for the decade ahead. The obvious intention is that this Charter will influence rehabilitation programs throughout the world to focus on the prevention of growing causes of disabling factors and the integration of the disabled into the community. In accomplishing this, the 1980 World Congress will have a true meaning and purpose for the next decade.

Let me briefly give you an overview of the program for the Congress in it's current planning stage. The opening event is planned to be an audio-visual presentation that would review developments in rehabilitation and changes in attitudes towards the disabled as seen through media presentation on disability and rehabilitation during the last 25 years. It is planned to have the presentation illustrate the change in pre-occupation with medical and technological developments to the current concerns with public attitudes that foster integration and the participation of disabled people themselves in the planning and development process.

Mr. J.R. Sarney
National Executive Director
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One Yonge Street, Suite 2110
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The first plenary session will focus on "*Integration*" and will direct it's concerns to the social reactions to difference; the fact that integration is the keystone to rehabilitation; the point that standardization and individualization is the dilema of the disabled.

This plenary session will be followed by sectional meetings that will deal with the components of integration and refer then to the educational system; community integration; vocational integration; integrated health systems and social integration. Each of these sectional meetings of course lend themselves to many specific subjects of discussion that will have the broadest possible interest to all of us in the field of rehabilitation.

There are two major workshops to be held within the Congress program and will be dealt with as specialized conferences on the themes of first, "*Disability and the Family*" and "*Participation of Disabled People in the Rehabilitation Process*".

The subject of "*Disability and the Family*" will be greatly influenced by discussions that are being held at this European Conference on Rehabilitation International which has had the theme of "*Disability in the Family*".

The World Congress workshop session under the title of "*Disability and the Family*" will be constructed under such dimensions as the following:

- Psycho-social impact of the disabled person on the family
- The family as a provider of care
- Parenting the disabled child
- A policy for family assistance
- Disabled parents and Parent groups
- Social costs of disability : economic impact on the family

We are confident that these dimensions will be broadened and further subjects of concern will be included.

The second workshop dealing with "*Participation of the Disabled People in the Rehabilitation Process*" will be concerned with subject areas that will deal with the consumer groups, their organization and function; research and service provider roles; economic pre-requisites to participation; self determination and planning for rehabilitation.

The second plenary session on "*Prevention*" will deal with the subject from all possible areas. Presentations will include such subjects as:

- etiology of disability and levels of prevention
- the disabling environment; and social dimensions of disability prevention

The sectional meetings dealing with the components of "*Prevention*" will cover PREVENTIVE HEALTH PROGRAMS which will include:

- at - risk children (pre and post natal concerns)
- at - risk families (genetic counselling)
- physical fitness and nutrition
- public attitudes towards good health

ACCIDENT PREVENTION will cover occupational hazards, traffic accidents, home accidents.

EARLY INTERVENTION PROGRAMS will deal with community screening; the family in early detection; early intervention and disability prevention; medical, social, educational and vocational aspects.

SOCIAL PREVENTION will focus on social security systems and diminishing dependence.

ENVIRONMENTAL HAZARDS will deal with noise and industrial pollution.

Getting back to the Congress product of the "*Charter for the 80's*", the procedure for the development of this document is to be undertaken in this manner:

There is a World Planning Group under the chairmanship of Mr. Alfred Morris, Minister for the Disabled of the United Kingdom. This group will have the responsibility of beginning the development of the "*Charter for*

This document will be drafted in association with the United Nations, the Specialized Agencies and the Standing Commissions and Regional Committees of Rehabilitation International.

It's concepts will then be given an opportunity for review at international conferences and congresses of Rehabilitation and the complete draft text is intended to be presented to participants at the 1980 World Congress for final review.

From our standpoint, as partners with Rehabilitation International in the organizing of the 1980 World Congress, we are delighted that this last day of the European Conference is being devoted to round table discussions on priorities in rehabilitation needs. This session will provide great input into final planning for that part of our World Congress theme that deals with "*Disability and the Family*". It should be a great bonus to our Congress programme.

If the "*Charter for the 80's*", produced by the Congress, provides the direction and guidance for rehabilitation in a uniformed and constructive manner that we feel it will, then the responsible organizations in rehabilitation throughout the world will all be directing their attention on important aspects that will have been determined - and a great step will have been taken on behalf of the disabled.

Finally, it is my great pleasure to extend a warm invitation to every attendee at this conference to come to Canada in June, 1980 (the dates are June 22 - 27) to be a part of this World Congress of Rehabilitation International.

Canada is a very big country, geographically speaking, so there is much for you to see over and above the benefits of attending a productive and valuable congress. I can assure you, on behalf of my colleages and the many volunteers and committees that are currently working on the 1980 World Congress, that your visit will be in total a beneficial, memorable and happy occasion.